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Translating Sweetness: Type 2 Diabetes, Race, Research, and Outreach

by

James Battle

A dissertation submitted in partial satisfaction of the

requirements for the degree of

Joint Doctor of Philosophy

with the University of California, San Francisco

in

Medical Anthropology

in the

Graduate Division

of the

University of California, Berkeley

Committee in charge:

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Spring 2012

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Abstract

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Through the lens of Type 2 diabetes this dissertation considers race and problems of difference and risk with developments in treatment, genomic science, and the conduct of research and research priorities. Based primarily on fieldwork in New York and California, I interrogate public health notions of *outreach* with biotechnology and clinical research concepts of biomedical *translation* as synonymous practices. Institutional relationships and marketing drivers, I argue, reflect relatedness back onto the Type 2 diabetes patient through causal narratives of risk and inevitability. In effect, kinship—genetic, familial, racial, ethnic, and environmental—becomes the driver of both risk and emergent forms of bioliterary discipline. I present a narrative of how diabetic risk became racialized over time and how African Americans became seen as a desirable research population. Arguing against biological race, I present an ethnographic example of how one such African American population, or community, emerged from particular social and political histories. Fieldwork uncovered lingering memories of the Tuskegee Experiment combined with cultural incompetency in both public health and biotechnology sectors. Further, I consider the bioethical challenges of African (American) participation in new genomic research aimed toward reducing health disparities. However, as a racial category, genetics researchers debate the precise genetic location and definition of "Africa" in the human genome. I suggest that the search for a pathological Africa in the human genome may deepen racial stigmatization as well as author new narratives of difference. I submit that social disparity, not biological disparity, presents the ultimate challenge to successful effective clinical translation and public health outreach.

Translating Sweetness: Type 2 Diabetes, Race, Research and Outreach

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Acknowledgments

This dissertation bears my name and indeed I have put an extraordinary amount of time and energy into the effort. However, it is also a product of countless hours of collaborative engagement both outside and inside the academy walls. I would like to thank my dissertation chair, Cori Hayden, for her patient guidance throughout the graduate school journey and her incisive commentary on my work. The readers on my committee – Nancy Scheper-Hughes, Michel Laguerre, Charles Briggs, and Sharon Kaufman – each brought diverse knowledge bases to my research and writing. I thank my entire committee for being models of scholarship and professionalism that I determine to emulate.

I would like to pass on my appreciation to the faculty-led dissertation writing groups conducted by Stanley Brandes at UC Berkeley and Sharon Kaufman at UC San Francisco. Stanley, Sharon and my colleagues greatly helped shape my early writing of this dissertation. Brad Erickson provided valuable editorial and organizational advice. I also extend my thanks to Cori Hayden's writing group in Fall 2009. Thank you Cori for bringing all of your graduate students together in one space of shared writing and critique.

Outside of the academy, I thank my contacts at the Alameda County Department of Public Health and the Diabetes Teaching Center at the University of California, San Francisco. In New York, I extend my gratitude to the American Diabetes Association, Mt. Olivet Baptist Church, and the Clinical Research Center. I would especially like to thank the entire Rochester community for their interest in my work and efforts to reduce health disparities in the area.

My inner strength to persevere through seven years of graduate school and the writing of this dissertation originates from the bottomless well of love that my family has provided during these travails: To my mother, Clara Doucet, my children Tashann and Leona, and countless aunts, uncles, and cousins, thank you. Suzanne, thank you for believing that I could become the next Ph.D. in the family. Heartfelt thanks to Regina Thompson for her love and support through my darkest hours and brightest days. And thank God for Facebook, which barely existed when I began graduate school, for helping me keep sane and expanding my own social network.

This dissertation research was funded by: The UC Chancellor's Fellowship, Ford Foundation Dissertation Fellowship, The Diebold Fellowship, The Ida Louise Jackson Dissertation Fellowship, and The George and Mary LeCron Foster Fellowship.

Preface

"The track sugar has left in modern history is one involving masses of people and resources, thrown into productive combination by social, economic, and political forces that were actively remaking the world" (Mintz 1985: 211).

My first encounter with diabetes or "sugar" was with my maternal grandmother, Bébé, a diabetic for the last thirty years of her life and the first twenty-five of mine. I lived with her and my grandfather in New York for most of the first twenty-one years of my life. I reveled in their stories of life in the South and the ways in which a life just recently lived but was no longer so, was narratively made close enough to feel, taste, and touch.

This sugar narrative begins with a Louisiana Afro-French Creole family from the Bayou Têche, deep in the Atchafalaya Basin of southwestern Louisiana. It was never profitable to the French, eventually becoming a frontier outpost (Fort Attakapas) occupied by hardy colonists and later refugees from Nova Scotia. Therefore in this area, slavery was originally a domestic form of the institution, with the average household having one or two slaves (Brasseaux 1994). The majority of these early Africans were brought from Senegambia under "favorable" conditions by decree of the French Crown, because of their expertise in growing rice, which the French hoped to feed their slaves in the more profitably extractive colonies of Saint Domingue (Haiti) and Martinique (Midlo Hall 1992).

After the Haitian Revolution, St. Martinville, Louisiana followed only New Orleans in the number of Haitian refugees who settled in the area. It was a refugee population consisting of planters, their slaves, as well as free people of color (*gens du couleur libre*). Shortly thereafter, several varieties of Haitian sugarcane were successfully bred which could withstand the infrequent but potentially devastating cold snaps that periodically descended upon subtropical southern Louisiana. Later, Norbert Rillieux, an Afro-Creole inventor educated in France, revolutionized the technology of sugar cane juice evaporation.[1] It was now a grand time in diasporic, transnational St. Martinville—a vibrant French language press; a French Opera House; the education of some children in France; and *Les Bals*—grand dances in the best of French costuming and masquerade.

However, it was also the site of numerous epidemics, endemic disease, and death. Yellow fever epidemics ravaged the area repeatedly throughout the 18th and 19th centuries. To illustrate the collective memory of those uncertain times of bio-insecurity—and present an example more deserving of historical attention and research—is a plaque in *le carré*, or square, outside the New Iberia Public Library.

It pays homage to Félicité,

> A black woman, native of Haiti. During the yellow fever epidemic here in 1839, she nursed the sick, administered to the dying, closed the eyes of the dead, and wept over their graves. Loved and honored by townspeople for the remainder of her life, she died in January 1852. The day of her burial, every business in New Iberia closed its doors, and every man, woman, and child in town

[1] Norbert Rillieux. US Patent 3237. *Improvement in Sugar Works*, US Patent Office, New Orleans, LA, August 26, 1843.

> followed her to her last resting place in St. Peter's Cemetery. She was an angel of mercy in a time of pestilence. Her name shall not be allowed to drop into oblivion.

Not your typical antebellum Southern narrative, the plaque gives an idea of the social nature of the area. It was an area slower than most in the adoption of Anglo-American racial discourses, categories, and exclusionary practices. In practice, its racial categories and social performances more closely resembled Cuba or Trinidad than say, South Carolina. Family, the Catholic religion, and (Creole and Cajun) French language and mores were as sharp as race in demarcating social difference.

Emerging within this milieu, my maternal family consisted of sugar cane farmers, *ésclaves*, workers, and plantation owners. Sugar production became an organizational axis around which kinship, labor, consumption, language, religion, race, and economic domains were reinforced and reconfigured through this particular form of engagement with praxis[2], history and the material, rationalized by capital. As a child born and raised in New York, my initial experiences with this familial past were sometimes hauntingly disconcerting when taking family trips to the bayou. The following illustrates one of these episodes:

When I was a young boy, we traveled by car to New Iberia, where we stayed with my Tantie (Aunt) Delores, a very large woman with two very large daughters, my favorite *cousines*, Josephine and Rena. One hot day, I opened the refrigerator, where before me sat an ominous looking pitcher of liquid, a cloudy solution made all the more mysterious by the refrigerator light shining through. I asked my mother, "What is this?" "It's sugar water," she replied. Disturbed, I asked her whether someone was going to eventually squeeze in some lemon or lime juice (to make it drinkable). She said, "No, people here drink *that* for energy."

My tender age notwithstanding, the only word which came to mind was, "slavery." This empty calorie drink, I imagined, was probably older than lemonade itself, a physiological necessity brought on by times I shuddered to imagine, much less accept. I was relieved to know that sugar water consumption was discontinued when our wing of the family moved north. Nevertheless, as both object and artifact, its historical, symbolic and interpretive power has since indelibly persisted in my psyche—all the more so since becoming aware of the practice throughout sugarcane growing regions of the Creole Atlantic world.

However, while newly cognizant of this particular historical form of sugar consumption, I was totally oblivious to the then contemporary forms of empty calorie consumption. We ate homemade German chocolate cake, made with hand-shredded fresh coconut and plus-plus portions of delectable local pecans. With this we downed entire cans of Hawaiian Punch. When one cake was finished, another was baked. This was breakfast—every day for a week. I was in bayou Louisiana, the land of sugar, a child's garden, where it seemed as if nothing sweet could ever possibly be considered culturally wrong — despite the fact that Rena, age 14, and Josephine, age 16, weighed approximately two hundred and twenty and two hundred and thirty pounds, respectively.

How do I know? Because we discussed weight openly—it never occurred to us that being large, alone, would make one less desirable or less self-confident. *Largeness* was not seen as a

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[2] By "praxis" I refer to Bourdieu's (1977) notion of a strategic mimesis embedded in reciprocal relationships structurally framed by spatial and temporal specificities through which power is refracted through subjects and objects.

barrier to life, marriage/partnership, children, family, to happiness.[3] "Sugar," the term used for diabetes was, like hypertension, something one acquired along the way, *sur la piste de la vie*.[4]

My diversion into personal family history both prefaces and foregrounds this dissertation within a chronology of my intellectual interest in Type 2 diabetes. Of course it also never occurred to us, as with most folks, that we were subjects and citizens produced by histories, economies, and environments shaped by power. However, labor, production, consumption, as well as an embodied state labeled and experienced around "sugar," was intimately known and perhaps fatalistically, accepted. The connections made by Mintz (1985) between sugar production, labor, globalization, capital accumulation, and nutritional inputs and outcomes across divergent geographies—and the ways in which societies and cultures are made and remade—echo strongly with my experiences as a member of a family embedded within these Creole histories, practices, and relationships.

Creole sociogenesis, "a theory of culture in relation to labor and capital, not a theory of bounded racial essentialisms," as Mintz and Price (1992) stated, undergirds my argument in this dissertation about "sugar" or Type 2 diabetes. Framings of Type 2 diabetes risk as racially (biologically, genetically) determined miss the conceptual mark: one of Type 2 diabetes as cultural affect in relation to consumption and capital, reflective of new forms of behavior, or labor. I suggest that the obesity and Type 2 diabetes pandemics arguably make moot any temptation to equate culture with race, biology with culture, or biology with race. I consider how *race*, *culture*, and *biology* mightily inform new genetic and genomic languages of human *difference*.

[3] See Nichter (2001:160)

[4] Adele Clarke (private communication) profitably suggests a line from the classic Martha Reeves and Vandellas' song "Heatwave" as an epistemological heuristic: "*Either my high blood pressure's got a hold on me or is this the way it's supposed to be?"* Illness as component of *habitus*.

Chapter One: Introduction

> *Indeed, over that last half century, at least in Euro-America, the pathologies, malfunctions, deficiencies, or suboptimal capacities of individuals and groups have become key sources of biovalue, and competition between states and corporations in the circuits of biovalue takes a very different form from the national struggles for supremacy that underpinned the rationalities of eugenics. It is for these reasons that I think we should conceptualize the economy of contemporary biopolitics as operating according to logics of vitality, not those of mortality.* (Rose 2007: 70)

This dissertation aims to show how Type 2 diabetes bioresearch today very much depends on the logics of vitality among both the living and the dead. I seek to untangle discourses of mortality risk animating efforts to enlist and enroll minority populations in new biopolitical economies of risk and race. Moreover, new genetic and genomic sequencing technologies provide new biological narratives of race and risk. They, too, seek genetic material from the living, but also the dead, troubling notions life, death, vitality, and eugenics. I endeavor to engage the ways genetics researchers, clinicians, as well as public health professionals, grapple with these sociobiological implications of race and risk.

I base this dissertation in part on biotechnology fieldwork conducted in the San Francisco Bay Area during the spring and summer of 2008 and from 2009-2010. I also performed community-based and clinical fieldwork in Rochester, New York during the fall and winter 2008-2009. Further, I traveled to meetings and symposia around the United States, listening to and speaking with health disparities experts, as well as genetics researchers. Understanding contemporary Type 2 diabetes, I believe, required a multi-sited fieldwork methodology and I found the geographic, economic, demographic, cultural contrasts compelling enough to weave together into this dissertation narrative.

I began this dissertation research project with an intended focus on how Type 2 diabetes technological advancement restructures categories of risk, as in the case of *prediabetes*. Whatever best laid plans they were a series of twists and turns awaited. In summer 2008, I learned about the release of a new diabetes risk prediction technology claiming to augur the chances of healthy individuals developing Type 2 diabetes within five years. During fieldwork, I later discovered that the biotechnology company which produces this new technology sought African American volunteers to test the predictive power of their instrument.

And now in 2012, the price of sequencing a genome is one twentieth than it was when I began this project. So what began as a project looking at diabetes from the perspective of phenotypical otherness based on group categories shifted to one based on genomic difference within individuals. Public health genomics as well as genetics counseling today exemplify changing institutional explanatory models of individualized difference and disease. The following pages of this dissertation trace each of these occurring developments.

I explore the role of race in the development of diabetes technologies that move the epidemiological clock backwards in time, from diagnosis to risk prediction of the asymptomatic individual. I was particularly interested in how diagnostic and now predictive assessment technologies have served to rationalize new pharmaceutical interventions and regimes of blood glucose control. In terms of the patient, this dissertation examines how these rational

interventions become operationalized within new moral economies and discourses or risk, individual responsibility, and personalized medicine.[5]

My research intention after the first year of graduate school considered inversely applying Sidney Mintz's earlier formulation in examining the rise of Type 2 diabetes in a former Caribbean sugar producing society. I thought of interrogating the inverted social and historical relationships involved in the production of new appetites and desires originating from the contemporary metropole in terms of new forms of consumption in the West Indies—both of empty calories as well as forms of cultural sedentism. This research equation necessarily was to include an analysis of how technology, as an historical factor in both the socialization and disciplining within plantation-factory, high-tech work and home environments, continues to shape Caribbean bodies through discourse and praxis in relation to capital (Cf. Freeman 2000).

While the intended research project remains a future possibility, preparatory archival and field research brought other, more necessary priorities to the fore. The more I researched Type 2 diabetes, the more acutely aware I became of both the technological and pharmaceutical interventions that were rapidly redefining the illness through the discourses they generated and circulated. I then came to the conclusion that I first needed to understand the clinical, market, and technological variables which were literally changing the face of Type 2 diabetes—as both a disease category and as a mobilizing rubric around which subjects, markets, and practices are organized.

To accomplish this, I decided upon a North American fieldwork project. In Laura Nader's (1972) words, my dissertation project became more "vertical" in its orientation and focus, enlisting Science, Technology, and Society (STS) and medical sociological perspectives in examining the institutional and market variables informing contemporary social understandings of Type 2 diabetes. These institutional and market variables driving technological advances in blood glucose assessment, their clinical interpretations, and patient engagement are the ethnographic and historical interlocutors in this dissertation.

During the summer of 2008, I conducted pilot research in both San Francisco and Rochester, New York. I attended Type 2 diabetes education classes and public health events in both community centers and churches. I spoke with physicians involved in recruiting volunteers for diabetes drug trials, as well as with representatives of national diabetes, kidney, and university research centers. I participated in diabetes walks, conversed with blood glucometer industry representatives, as well as with Type 2 diabetics, and their families and friends I met just by mentioning my research at social gatherings, church picnics, cafés and restaurants. I quickly learned that there is no shortage of people willing to talk about diabetes.

So I found myself diving into an unforeseen dissertation project that I had been well prepared to conduct. Yet, my own positionality as an ethnographer researching Type 2 diabetes was double: I was researching an illness that I presumably did not have, however; I belong to a

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[5] I use *moral economy* after Thompson (1971), particularly in terms of the political economy of food and *social* affect. This dissertation engages the ways in which the asymptomatic individual, prediabetic, or Type 2 diabetes patient is brought into new discursive and technological relationships, or rather technosocialized, into new moral economies of behavior about food, the body, and *biological* affect. I further extend my employment of the term to Kohler's (1999) example of a unique positive moral economy of practice amongst Drosophilists (researchers of the fruit fly, *sp. Drosophila*). He concluded that low stakes science affects a moral economy of "mutual aid," and high stakes scientific research (such as in the lucrative T2D market), a negative moral economy of secrecy and ethical ambiguity (Kohler 1999: 254-255). I

high-risk group, all the more so for having had a maternal grandparent with the illness. This brought with it some phenomenological and methodological concerns.

The At Risk Ethnographer of Risk

At the beginning of this project in 2008, I debated whether I should obtain either an Oral Fasting Glucose Tolerance Test (hereafter referred to as the OGTT) or a Hemoglobin A1C (or HgA1C) test to determine my insulin resistance. Being guilty of eating the occasional late night dessert and falling into rather sedentary ways over the recent years as an aspiring academic, I wondered if there was a price to be paid for the extra pounds of flesh gained in process. Coupled with the risk factors mentioned previously, I honestly harbored a lingering sense of apprehension for some months concerning precisely where my body was situated in relationship to this dissertation research project.

I was reminded of Lawrence Cohen's (1995) dual observation and interrogation of medical anthropologists, historians of medicine, and scholars of traditional, complementary and alternative medical (CAM) practices, about the very question of locating the scholarly body in proximity to the practice studied and authored. Cohen pointedly asked: "Whence the seduction? (1995:325)" My fears of incurring both kinship and practitioner karma through the possibility of either a Type 2 diabetes or prediabetes diagnosis (given extra heft by my mother's recent diagnosis of *prediabetes*), began wearing away the more I indulged Cohen's reflexive imperative.

Then I met Darlene Pedraza at a diabetes education class in Livermore, California. A diabetes educator working with the Alameda County Department of Public Health, Darlene and I had been connected by her boss, Betty Washington. Over the course of summer 2009, I was fortunate to shadow her in the field, conduct interviews, and attend her classes. An energetic and knowledgeable teacher, Darlene and her associate Hector Elizondo offered to test me for Type 2 diabetes—at our very first meeting.

As an anthropologist, I found myself caught rather off-guard by the offer. Envisioning that stage of my research methodology as more observation than participation, I was decentered from a stance of analyzing to being analyzed. As previously mentioned, my membership in a *high-risk group*, academically-induced corpulence, and having had a diabetic grandmother, a *prediabetic* mother, and the associated discourses of risk surrounding such pathological forms of kinship swirled through my mind. Deciding to face the "facts" with a mixture of curiosity and dread, I accepted the offer.

"This won't take but a minute James." Hector said as I presented my arm. "Just think, only a few years ago you would have had to go to the clinic to take this test," he added. Using a new portable Hemoglobin A1C testing unit produced by Bayer, field clinicians can now accurately measure the glucose metabolism of a red blood cell over the roughly three months of the cell's lifespan. This gives greater diagnostic reliability over other testing technologies. For example, the glucometer can only measure present blood sugar levels, although newer models can store weeks and months' worth of data, which can even be sent directly to the physician or clinician's office. I will delve more deeply into these technologies later in the dissertation.

The finger prick was barely noticeable, barely warranting mention. Having always been rather squeamish about needles and other invasive procedures, I was surprised at the relative absence of pain. Hector's pre-test assurance of a quick test was not taken as an assurance of a pain-free test. I had heard that line before and was prepared for the worst in terms of pain—and the worst in terms of diagnosis. So far, I was wrong about the needle. Now, for the result.

Extracting not a vial but what I can only call a smidgeon of blood, the HgA1C device took perhaps a minute to analyze my blood glucose metabolism. Or at the very least, how it had been behaving metabolically over the course of the last three months. During that minute, I had uncontrollable visions of future performances of therapeutic contrition and penance: salads, bike rides, walking around Lake Merritt every morning, yoga classes every evening, pilgrimages to farmers' markets every week, and a gym membership for everything in between.

"5.1. …" Hector announced as the number flashed across the device screen. "... Perfect!" Instantaneous joy and relief competed for my attention. However, certain confusion punctuated these initial sentiments. Had I averted the pathologies of kinship? Or were race and kinship still there, somewhere, perhaps lingering in the deeper biological recesses of my genetic and genomic destiny, waiting to emerge, and waiting to strike?

Frankly, as a comparative public health and historical disease phenomenon, I was more nervous about taking a diabetes test than I had been in taking my first HIV test. How the epidemiological and prognostic landscapes have changed: an individual with HIV today, with proper medication, can hope to live a quality life—in many respects better and longer than someone with Type 2 diabetes. Perhaps it is true that one never knows what one is being prepared for until the definitive moment arrives which will offer an explanation of the past. However, the pervasive spread and growth of Type 2 diabetes diagnoses, the development of diagnostic, predictive, and self-monitoring technologies, the new classificatory categories of pathology these devices create and leave open to reinterpretation, and the market interests informing them all, animate both my efforts and goals of this dissertation from the dually socially constructed *categorical* imperative of race and *technological* imperative of risk. I seek to show that while group attributions of race may give way to individualized attributions of risk based on difference, racial group categorization remains embedded in both genetic/genomics and population health languages.

In connection, I make the economic argument that Type 2 diabetes disease risk and market risk are inextricably woven together. Secondly, I suggest that high-risk T2 population groups play an important role in adding value to both biotechnology and pharmaceutical commodities. I ethnographically charted biotechnology and clinical research attempts at outreach to and procurement of African American participants for Type 2 diabetes trials. I gave concomitant attention to the relationship between the market and the forms of inclusive citizenship it makes possible, and how this informs contemporary obesity amongst low income, minority, and immigrant groups.

I raise the bioethical implications of these historical and continuing interactions and intersections of race, ethnicity, class, and gender. I present a picture of the cognitive relationship between Type 2 diabetes blood glucose measurement technologies and the virtuous subject charged with the personal responsibility of caring for himself and controlling her diabetes—in the midst of shifting discourses, technologies, and categories of both biological risk and market speculation. The contemporary biological value of racialized bodies today, I will argue, primarily lay not within the social capital of the group. It exists within the calculated genomic differences within and among individuals, as part of the premise and promise of personalized medicine.

Race, Genes, and Bio-logical Value

Through the lens of Type 2 diabetes, I aim to (re)define "race" as a classificatory system driven by political and economic forces which create new forms of biovalue (DuBois 1940, Mitchell and Waldby 2006, El Haj 2007). What I seek to illustrate in this dissertation is that

racial categories used in clinical, public health, and genetic/genomic research are as inherently instable as earlier social scientific concepts of stable societies. I argue, therefore, against notions of stable biologies. *Race* has no "essence."

As a student and later scholar, WEB DuBois saw definitions of race shift literally under his feet from the late 19th to mid-twentieth centuries. Born in 1868, he matured and lived through Spencer's Social Darwinism, Tylor and Morgan's hierarchies, the "science" of 19th century biological anthropology, Marxism, structural-functionalism, and the culture concept. In Dusk of Dawn: An Essay toward an Autobiography of the Race Concept (1940), DuBois sought to reconcile his personal identification with Africa with the legacy social category "Negro" inherited through slavery. Writing an elegant genealogy of his "mixed" background, DuBois argues against the biological heritability of race or for that matter, racial self-identification. Race and self-identification inhere themselves to a political economy of productive instability. Simply stated, for DuBois, the shifting winds of political and economic fortune reshape individual, social and biological notions of race.

In anthropology, Edmund Leach (2004 [1954]), Edmund Leach contested canonical notions of stable social and cultural categories. Originating in Durkheim, the idea of stable societies had no positive concept of change, much less one based on its necessity for cultural adaptation through discourse and the machinations of power. These ideas proved untenable for Leach, who made room for agency and human calculation as drivers of structural change. It is instructive that his structural break with functionalist ideas of equilibrium was informed by Lévi-Strauss, whose theory of structure was not entirely fieldwork-based (Leach 2004: 7-10).

What is also instructive is that any contemporary somatic analysis, especially a comparative one, is undeniably informed by the very structures of power, agency, and their changing forms considered today constructive of the body itself. Leach's notions of disequilibrium within cultures brought on by structural change, superimposed onto Evan's-Pritchard's rational relativism, brings new understandings and ways of ethnographically gazing at the body. No longer "stable" (diachronic) members of "stable" societies, somatic representations of the "the other" had to change. Margaret Lock's work on menopause in Japan and North America is an excellent ethnographic case in point.

Lock deconstructed Japanese history through its myths as informative of how bodies are culturally produced and subjectified. In Encounters with Aging (1993), Lock posited that all bodies, in this case Japanese female ones, are ideologically produced. Subservience as a conditioning process varies according to historical and cultural influences, which in Japan, "...fit into a particularly hegemonic situation" (Lock 1993: 204).

The specificities of biological change resulting from changing historical and cultural practices add new variables which challenge notions of stable racial categories. Race as a socially constructed biological value has been commodified in genomic and postgenomic research, posing questions about the permeability of the nature/culture divide in articulating new biological forms of difference and risk. Michael J. Montoya (2007,) interrogated the ways in which genetic researchers allocate clinical meaning to DNA fragments assignable to poorly-defined ethnic and racial populations. However, Montoya argues that ethnographic attention needs to be placed upon racial categorization as a research method to better understand how biological attributes are imbued with racialized meaning by genetics researchers (Montoya 2007). Diversity itself is the object of biovalue fueling both political and scientific projects, bringing together inclusive notions of biological, consumer and medical citizenship, all of which reinforce research imperatives (El-Haj 2007). Even when ethnographic data shows subjective

confusion about race, both in terms of autobiographical and social meaning, genetics researchers interviewed subsumed such discourses in the face of research protocols based on *objectively* constructed racial categories (Fullwiley 2007b).

Montoya, Paradies, and Fullerton (2007) question the ability of the thrifty genotype hypothesis (THG) to explain the high prevalence of diabetes and other cardiometabolic[6] disorders among "high-risk" populations such as Native Americans, Latinos, and African Americans in the absence of an examination of the environmental, political, economic, and nutritional histories of these populations. Nevertheless, longstanding, now naturalized, notions of race and phenotypical difference attract investment into genetic research into diabetes amongst "at risk" populations. The authors suggest that this approach may yield imperfect research results and contribute little to actually understanding diabetes.

At the beginning of this century, some voices in public health saw race and ethnicity as vital components of culturally competent health care. Erasing race and ethnicity would in their view, diminish the predictive power of public health models, resulting in lost opportunities to target interventions towards those groups harboring the greater preponderance of medical risks. Scientific progress would be lost, they argued, toward better understanding race and ethnicity as either biohazardous or bioprotective (Mays, Ponce, Washington et al. 2003).

Despite the fact that all humans share 99.93% genetic affinity, genetic and genomic research continues to focus on the 0.97% genetic difference among human populations. In Inclusion: The Politics of Difference in Medical Research, Steven Epstein (2007) examined how medical knowledge "…attends(sic) to difference–equating group identities with medically distinct bodily subtypes–precluding(sic) direct attention to reducing inequalities in the domain of health. …" This epistemological stance furthers both discursive and methodological scientific practices driving research medical research through the prism of biologized race and sex. These discursive and methodological stances inform patient epistemology concerning health access and health disparities in terms of the subjective experience of patienthood; and, the objective reality of epidemiological data (Epstein 2007:3-4).

Drawing on Weber's (1947) "irrationality of rationalization," Fullwiley (2007b) argues that biomedical research based on race "runs the risk of irrationalizing both" medicine and race (Fullwiley 2007b: 235-236). As DuBois understood in 1940, the instability of racial categories lays bare the irrationality of sociocultural preconceptions about human difference as open to biological explanation. This new "inclusion-and-difference" paradigm is driven by older epistèmes of group difference as biologically ascertainable in terms of "race": this is evidenced by the paucity of research extrapolating genetic research across heterogeneous populations and putative categories. As such the white male standard has new company with respect to old phenotypical acquaintances with whom it now shares both political and biomedical research space (Epstein 2007:6-7). However the epistemological and methodological errors remain intact—"race" as a genotypically-fixed final destination (or stable category, in equilibrium)

[6] The *metabolic syndrome* (MetS) comprises a constellation of conditions, which includes: obesity, hyperlipidemia, hypertension, hyperglycemia, renal disease, eye disease (retinopathy), and nerve damage (neuropathy). The combination of these conditions has a negative effect on cardiovascular health, hence the term *Cardiometabolic Syndrome*. However, the cardiometabolic syndrome is not seen as sequelae to the metabolic syndrome – the terms are used almost interchangeably. Unless quoted, in this dissertation, I will employ the more descriptive term *cardiometabolic syndrome*.

which is scientifically discoverable *rather* than a moving target. This presents an intractable form of social and scientific classification.

DuBois' political economy of sociobiological race and racial (self)-identification echoes into early twenty first century scholarship. Nelson (2008) argues that new genetic forms of racial classification have created new forms of social meaning around identity. Genetic tests as a commodity offer new tools for "self-fashioning" based on notions of scientific impartiality, an object means of fulfilling one's "genealogical aspirations." While Nelson suggests it premature to assess the social and political ramifications of newly marketed genetic "ancestry" testing models, she submits that the knowledge claims they make, as well as their subsequent interpretation by the consumer, set in motion new forms of subjectification based on biological notions of racial difference (Nelson 2008: 776-777).

Note that I would have preferred to italicize *African American(s)* in this dissertation to contest biological assertions of race as well as to highlight the political, economic, and spatial factors that have historically shaped the category. By inclusion, I would also have italicized *Latino(s), White(s)/Caucasian(s), Native Americans*, etc. in attempting to refocus critical attention to the effects and affects of power and its invisible capacity to author visible narratives of biological and phenotypical ascription. However, in this process of italicized ascription, I would have scarcely conveyed both my own ambiguity and duplicity in the matter. Ambiguity, in that as an anthropologist, I do not subscribe to theories of biological race. This theoretical refusal is embedded within the critique I seek to make in this dissertation concerning the ways in which race is envisioned and deployed not only in clinical research, biotechnology, and public health arenas, but in the academy as well.[7]

On the other hand, by scripturally referencing racial categories, I admit duplicity in participating in both their historic and contemporary reproduction. However, I aim to trouble this duplicity with a critical ambiguity which more clearly highlights the instability of such categories with ethnographic data gathered from fieldwork amongst both health disparities and population genetics/genomics researchers.

Risk

My research foray into contemporary Type 2 diabetes required a disentangling of the different disciplinary and conceptual notions of risk driving different actors within and across social, economic, and scientific fields. These languages of risk inform each other with varying degrees of concordance. This does not mean that these languages of risk are either mutually intelligible or mutually aware. What I endeavor to consider in this section centers around how risk has come to describe the contemporary world we inhabit today.

Douglas and Wildavsky's (1982) work on the dangers posed to and by those inhabiting various socially constructed spaces of risk, in its ethnographic data and analysis, has become a canonical text in the anthropology of risk. They remind us that all effective healing involves ritual within a space where disorder, impurity, discord, and the socially-constructed perceptions of the dangers or risks they represent can be rectified.

In his classic on economic risk, Franklin Knight[8] argued that economic risk in relation to profit can be defined as "measurable uncertainty," or, better still, "true uncertainty."

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[7] I use pseudonyms for all personal names used in this dissertation. I also employ pseudonyms for most professional and institutional names as well, excepting those already in the public domain.

[8] *Risk, Uncertainty, and Profit* (1921).

What is interesting about Knight's notion of economic risk as grounded in quantitative assessment is that he relegated *qualitative* risk to the realm of uncertainty. Immeasurable uncertainty, he argued, must be analytically distinguished from *true* uncertainty, or risk. Further, I must remind that Knight saw his work firmly grounded in economics as a social science, a study in method, of how social organization could better drive economic cooperation in the pursuit of improving social life.

However, in this pursuit, Knight argued for bracketing out both defense and critique of the capitalist system. It was his opinion that without first completely understanding the system under examination, it should neither be prematurely valorized nor devalued. Yet, within Knight's conceptual and methodological parameters what was left outstanding was an examination of power, control, and affect, both economically and socially. Needless to say, a political economic critique of the epidemiological consequences of power and affect remained unexplored.

Later, Beck (2006) extended Knight in arguing for a necessary distinction between economic and sociological notions of risk. Beck placed emphasis on the question of power and control. He argued that regimes of control based upon calculable forms of predictive risk should be differentiated from incalculable forms of risk without precedent. The rationality of the former cannot anticipate the irrationality of the latter. Both forms of risk, the calculable and the incalculable, Beck maintained, comprise the contemporary risk saturated world we inhabit. Inhabiting risk, therefore, is a means of both being and being ruled in the contemporary world (Beck 2006: 2-3; Woodward 1999).

The Molecularity of Risk

Foucaldian biopolitics as a practice has shifted since its 19th century origins, with accompanying shifts in its gaze; from the scrutinizing and classifying of pathology *among* bodies in relatively homogenous, whole populations; to that of post-genomic regimes of intervention based upon calculative agencies of epidemiological risk based upon diversity *within* bodies. These notions of risk are themselves the product of the foundational biopolitics of 19th and 20th century accounting, public health, and actuarial stochastics (Beck 1992a, 1992b; Luhmann 1993, Giddens 1999, Rose 2007).

As both capitalized affect and phenomenology, inhabited risk, I argue, introduces the notion of a risk managing subject (Beck 2006). The therapeutic epistemology driving this risk managing subject, who is also a patient, consumer, and citizen, is the notion of choice, of agency. However, it is presumed that this laboring risk managing subject is a (bio)literate, rational actor whose choice reflects the logic of risk aversion, or *care*, inherent to the choice itself.[9] Most importantly, both Knight and Beck pointed to the technologies of risk which make possible advancements in the very risk assessment methodologies and interpretive schematics to which they both alluded. They both accurately pointed to the productive, even profitable, ambiguities generated through risk assessment, which the post-event (or for our purposes, diagnosis) could not achieve in the past. Despite Knight's insistence on risk research as part of an overall improvement in social life, his argument failed to take into account the disruptive social consequences which economic scientific rationales of risk and profit can wreak upon societies, markets, and bodies. Later, Beck (2006) normalized this disruptive capability as a rationalized principle of power, society, and the body.

[9] Mol (2009) The Logic of Care.

In The Politics of Life Itself (2007) Nikolas Rose traced the privatization of the state's promise in manifesting Agamben's "good life," through new calculative agencies of risk which created new citizen-consumer-subjects as well as market share. Foucault's notions of sex and control cohere with the conflation of eugenics and preventative medicine over the course of the twentieth century. *Fitness* rather than health, a mechanistic prognostic episteme redolent of industrial age and capitalistic rationales became the criteria for evaluating human life. Eugenics as risk prevention was to expand into the medicine of risk, as risk became a therapeutic target and "eugenics" a misleading thought of historical aberration. But what was left untouched was the notion that human life could be improved, a notion which over the twentieth century shifted from one of *national fitness* to one of *individual fitness* (Rose 2001, 2007).

New twenty-first century forms of subjectification through novel genetic explanations of race and biological risk extend to longer standing notions of race and crime risk, conflating public health with public safety. Both forms of risk require different modes of surveillance and biopolitical control. Genetic testing arguably serves a potential role in linking new discourses of public health and public safety by attempting to locate behavior in the gene. With more African Americans in prison than were enslaved in 1860, mandatory DNA testing upon incarceral intake has assumed frightening proportions (Roberts 2011: 296-298).

Both financial and biosocial risk has become tangible market instruments which reconfigure not only Type 2 diabetes, but also the very milieux within which the illness emerge. Knight could have scarcely imagined that a science of risk which could successfully anticipate profit would one day reify, package and commodify risk itself—as both a market product and mode of living in the world—and as a technological form of biological (self) governance.

Translation and Outreach

In this dissertation, I present race and risk as significant drivers of Type 2 diabetes biomedical translation and public health outreach. I link outreach to translation (in ways that I see as sharing both synonymous and dialectical meanings). Synonymous, insofar as, simply put, the translational process ostensibly aims to convert the language of science, in this case the science of Type 2 diabetes, to the language of the patient. This definition of translational medicine, commonly referred to as *bench to bedside*, is but one interpretation of the term. A more contemporary interpretation defines translational medicine as the conversion of "venture capital funding into market profitability" resulting from the creation of biomedical commodities, technologies, and services (Butler 2008).

The co-production of science and society through translation and outreach requires a political-economic analysis in order to untangle the messiness of these collaborative and contested engagements. I present translation and outreach within a dialectical paradigm by illustrating how public health outreach efforts to the public exist relationally to changing interpretations by different stakeholders in the translational process. *Outreach*, so conceived and executed, depends on a degree of fixed certitude about the translated language of Type 2 science in communicating with the public. Further, I present two ethnographic examples of how two private companies, one in biotechnology and another in pharmaceutical clinical trial recruitment, both found public outreach indispensable to their respective translational projects. In each instance, attempts at successful outreach failed, leaving bare the cognitive dissonance and incommensurability resulting from a lack of social understanding about the African-American populations they sought to engage.

Attempting to Connect

Anthropological scholarship on translation has examined the social production of incommensurability (Briggs and Hallin 2007, Povinelli 2001). Briggs and Hallin suggest that new categories of risk are created through forms of inclusive citizenship based on notions of biologized difference (Briggs and Hallin 2007: 43-44). Built upon their earlier (2005) discursive model, or authoritative proficiency in targeting audiences based on difference and communicating risk to these audiences through the lens of difference (2007: 46) Briggs and Hallin point to a dual process of racialization and medicalization (2005: 270-271). Incommensurability is built-in to Briggs and Hallin's model, or the ways in which both translational medicine and public health outreach are communicated to both individual patients in private spaces and to the public in public spaces. As an ideology of power, it circulates, not only to targeted audiences, but through and amongst these audiences, then back to their discursive progenitors. As a model of the discursive circulation of medical risk based on difference, communicating science not only reconfigures nature but who is situated where and how securely within its confines.

Elizabeth Povinelli (2001) argued that through different symbolic forms of communication, people receive various messages as to

> how they should calculate and calibrate the stakes, pleasures, and risks of being a certain type of form in a certain type of formed space. Drawn into the semiotic process are the formal and inform(ation)al institutional forces that dictate the varying degrees of pleasure and harm varying types of people face breaking frame—of having the wrong body, or wrong form of a body, or wrong attitude about that formed body in a (informed) formed world (Povinelli 2001: 325).

In the case of Type 2 diabetes, presumably, the African American, Latino, and Native American body is the "wrong body" to inherit, but the right body for clinical research, diabetes education, and public health stakeholders. However, the obese body, one "wrong form of a body," as I present later, troubles notions about the racial genetics of obesity prevalence in contemporary (global) US society.

Trajectory

I have taken up the difficult task in this dissertation of ethnographically weaving together many complex strands of theory, practice, and experience into a coherent narrative about a seemingly simple disease to understand, Type 2 diabetes. I was interested in the social, cultural, and economic factors which make it a complex disease with regard to practice, both for patients and clinicians. I challenge clinical and biomarket assumptions of the *individual* patient charged with the moral economy of personal responsibility to health in contradistinction with the patient as a biological member of a *group* at risk.

In this dissertation, I explore the areas of race, outreach, translation, and risk in attempting a critical examination of the "emerging genetics stranglehold on explaining disease causality" (Montoya 2011: 190). While cognizant of and in disagreement with genetic/genomic narratives of race and diabetes engaged in other works (name), my point of ethnographic departure in this dissertation project followed how these narratives shaped public health outreach, and biotechnology and clinical research translational efforts in the San Francisco Bay

area and Rochester, NY. I examine one African American community and the ways in which it imagines and experiences Type 2 diabetes, as well as sees itself as a historically targeted research population. I present a narrative about race, risk, outreach, translation and the forms of surveillance they attempt to instill in engaging how incommensurability is produced and aversion to public health and bioclinical entreaties of inclusion and participation viewed, if not suspiciously, then certainly not as value-neutral discourses and practices.

OVERVIEW OF THE DISSERTATION

I present this dissertation as an intellectual invitation to think through the definitions and interpretations of treatment and prevention and the challenges facing translational medicine in addressing health disparities. It is not a metanarrative of the phenomenon, but rather a composite ethnographic picture of the contemporary of biotech and public health framings of Type 2 diabetes risk and race. The second chapter gives an historical and genealogical overview of how diabetes has been researched, understood, framed, and diagnosed over the last century.

Specifically, I focus on diabetes classificatory history and the technological advances which have moved us from clinical diagnosis to clinical risk prediction. I connect how the lack of endocrinologists complicates and brings urgency to Type 2 diabetes phenomenon and rationalizes the development of new technological forms of expertise.

In the third chapter I examine new diabetes technologies that now claim to predict future diabetes risk in otherwise healthy individuals. However, still extant racial categories and their scientifically imagined members continue to be seen as important research populations of risk to both biotechnology and biomedical researchers. I examine one company's efforts to recruit US African Americans to test their new diabetes risk score technology in hopes of increasing the clinical and market value of their product. I present an ethnographic narrative of the ethical and translational challenges affecting this company's recruiting efforts. I argue that while neoliberal discourses of diversity and inclusion (Epstein) have increased the biovalue (El-Haj) of these populations, in this case African Americans, a translational wall still exists between research communities and targeted risk groups.

The fourth chapter looks at historical and contemporary factors affecting African American apprehension and reticence toward participating in biomedical research and the role of churches in performing the work of medical translation. I show how the Tuskegee Experiment still resonates in the social body of the community and the role African American churches may play in communicating the biomedical message. Of equal importance, I argue that African American professional representations of biomedical messages within a church venue allowed for greater acceptance public health Type 2 discourses and programs. However, as a "total institution," I suggest that the African American church, while not monolithic, remains the center of real and imagined African American life (Du Bois 1899, Anderson).

In Chapter Four, I engage the topic of contemporary obesity, the role of technology in contributing to the phenomenon and today and offered as a therapeutic solution to our increasingly sedentary lives. I analyze the political economy of food, eating, race, and citizenship and what they mean in terms of new forms of socialized inertia. Through this lens, I examine the *African American* struggle for public access to food during the Civil Rights movement. I extend my examination to the role of stress in influencing eating behavior as well as attitudes toward exercise. I further interrogate the linguistic shift from *exercise* to *activity* and the work this does to (mis)inform what exactly constitutes metabolically sufficient physical movement. I argue that these symbolic forms of inclusive citizenship through public consumption once offered to

African Americans but also now to immigrants as well as those of lower social economic status, trouble public health and other intervention programs targeting at-risk diabetic and obese populations.

Chapter Five examines race and health disparities in light of recent advances in genomic sequencing technology. In Chapter Six, I conclude by offering a synthetic view of the preceding chapters in reckoning future spaces of possibility and constraint. From this research I argue that anthropological assertions of race as having no biological basis would prove more productive than Type 2 diabetes research. However, racial and ethnic risk categories employed in clinical and biotechnology research value racial difference as biologically significant and market desirable. I conclude that research preoccupations with race, at least in the case of Type 2 diabetes, reproduce race as a biological given.

Finally, I submit that contemporary obesity and Type 2 diabetes transcend race or region. These physiological changes have occurred in both segregated and desegregated social spaces. Race and risk take on different forms with different faces depending on the biopolitical or biomarket rationalities of specific Type 2 audiences in specific national and/or market spaces. In the US, research attention remains focused on biologically valuable at risk minorities, such as African Americans, Latinos, and Native Americans, which I challenge on ethical and categorical grounds due to the forms of social and geographic distance that leave these populations vulnerable to inappropriate research practices.

Laying Out the Social Field of Type 2 Diabetes

This research explores Type 2 diabetes by comparing and contrasting clinical data with social network data. My project employs Adele Clarke, et al.'s (2010; 2003) use of "biomedicalization," or the technological and scientific expansion of medical practice, by examining how glucometer and other diabetes technologies are embedded within new social forms and emergent practices transformative of both medicine and patient. In this attempt, the dissertation aims to trace the translational process from clinical objectivity to rational patient/consumer behavior, what I call *technosocialization*. Technosocialization introduces the notion of a patient/consumer who *labors* in new ways organized around new technologies that not only index metabolic risk, but also their discursive norms, pathologies—and their boundaries (Cf. Thompson 2005).

Employing Clarke's notion of *biomedicalization*, I seek to chart how experts both create risk and instruments of predicting Type 2 risk through discourses of racial risk and moral economies of individual patient responsibility. Accordingly, this research methodologically assumed George E. Marcus' (1995[1998]) questioning of the relevance of traditional fieldwork within singular geographic and theoretical rubrics in an ever increasing global world where people, ideas, objects, technologies, capital, and institutional power have helped redefine and reshape the local (and the epidemiological). This ethnography interrogates not only these varied spaces and actors, but also how the field itself is constituted by the ethnographer from her positionalities within and between these multi-sited research spaces.

During May and June 2008 I regularly attended diabetes education classes at the Diabetes Teaching Center at UCSF, as well as at public health and community organizations in the SF Bay Area. Through informal conversations with patients and staff as well as participant observation, I became aware of how Type 2 diabetes management is communicated in terms of blood glucometer control as an individualized practice. I learned that only seven percent of Type 2 diabetics actually achieve acceptable blood glucose control.

The upstate New York portion of my fieldwork occurred in fall 2008, as well as yearly follow-up visits in 2009 and 2010. I chose the area because it had been a relatively prosperous region until the early 1980s when local industries began laying off large numbers of workers—a process from which the area is still seeking to recover. However, local politicians continue to campaign on the promise of returning manufacturing jobs to the region. It is an area where the global realities of the contemporary economic situation have been slower to materialize. Behind this is a region with among the highest levels of both Type 2 diabetes and cirrhosis of the liver in the state, which perhaps suggests a link to depression—something not out of the question given the socioeconomic realities alluded to—and one of the most underappreciated contributors to and exacerbating the increase in Type 2 diabetes.

My vertical ethnographic approach entailed embedded participant observation at: 1) diabetes education classes; 2) public health conferences and symposia; 3) university medical research centers; 4) Diabetes technology patient focus groups; 5) diabetes technology companies and venture capital firms. I conducted informal and formal interviews in order to explore how diabetes risk technologies and practices are communicated horizontally *across* public space. Toward this goal, I began by recruiting four formal interviews from each of the above five ethnographic sites to outline the ways technology affects how Type 2 diabetes publics are imagined and reshaped by both state, institutional, and market actors. I generated these interviews from participant observation, placing attention on the relationships between the American Diabetes Association, the American Heart Association (AHA), and biotechnology and pharmaceutical interests. My examination of these diverse interests and relationships endeavored to understand how diabetes risk technology is authorized and communicated to the "public" through public health campaigns and policies.

Fellowships from the MD Anderson Cancer Center in Houston, Texas and the Department of Anthropology at the University of North Carolina, Chapel Hill permitted me to deepen my research on health disparities on minority, particularly African American communities. A fellowship from the Department of Anthropology at UNC Chapel Hill allowed me to more profoundly explore the medical genetics and genomics of African and African descent populations. These field sites provided an opportunity to meet, interview, and learn from leading researchers and scholars in the fields of health disparities, epidemiology, bioethics, public health, and population genetics.

I also conducted archival research in public health, epidemiology, clinical medicine, as well as Science, Technology, and Society Studies (STS), medical anthropology and medical sociology. I interrogated biomedical and anthropological notions of difference as methods informing historical and contemporary practices of biomedical and ethnographic explanation. The scriptural and moral authority to account for and validate difference, once the province of theology and philosophy, claimed in the 19th century by biology, ethnology, and anthropology, today exists in biogenetic articulations of human biological variation (Jhally and Hall 2002). What has not changed, I argue, is the notion of human diversity as states of exception rather than the state of nature. These states of exception persist in the form of racial categories utilized as explanatory models of both disease risk and disease incidence (Fullwiley 2007a, 2007b, 2008; Braun, Fausto-Sterling, Fullwiley et al. 2007). And as we shall see, these racial categories also serve to operationalize research and intervention strategies. I wish to demonstrate that while race as an imprecise theory remains prominent, attention should be given to how race has become an imprecise *method* toward achieving measurable research and public health outcomes.

Chapter Two: Framing Diabetes

> *The problem of understanding the genetic nature of man is both a philosophical and, in the days of rapidly changing environment, a practical challenge. Progress demands both a broad approach on the theoretical level and a very specific approach geared to particular traits presenting favorable analytic opportunities. Diabetes Mellitus may be one such trait. In this essay an hypothesis has been advanced which envisions diabetes mellitus as an untoward aspect of a "thriftiness" genotype which is less of an asset no than in the feast-or-famine days of hunting and gathering cultures. Specific means of testing the hypothesis are suggested. (Neel 1962: 360).*

In 1962, James Neel posited that hunter-gatherers possessed a "thrifty gene" which allowed them to withstand environmental fluctuations and the vicissitudes of feast and famine in sparse, mostly arid environments. Neel saw "progress" as the material and technological enabling of a modern culture of sedentary living in the midst of caloric abundance, leaving these groups uniquely susceptible to the ravages of obesity and diabetes. Populations most recently removed from hunting and gathering, Neel argued, would be more genetically susceptible to both obesity and diabetes (Neel 1962).

Although he never overtly mentioned race in the article, subsequent interpretations of Neel's hypothesis racialized his argument, with southwestern US *Native Americans* and *Latinos* with *Native American* ancestry offered as the model populations of feast or famine physiology. Of particular interest is how Neel's vague hypothesis became a model of racial specificity, and even more vague, the history of just when this interpretive transformation actually occurred (Fee 2006). However, herein lay the problem: Neel proposed two possible future Type 2 diabetes epidemiological scenarios and the genetic implications of each. Under the unambiguous heading, "Some Eugenic Considerations," the first scenario couples the globalization of western diet and culture with advances in population health. This Neel argued, would result in an increased population of individuals with the "thrifty genotype." In the second scenario, high population pressure resulting in periodic food scarcity would render the thrifty genotype useful in a similar way that sickle-cell anemia serves as an evolutionary bioprotective to malaria (Neel 1962: 359-360).

Neel left out whether western medical care would be available when things turned bad in the rest of world. Later, he would stand accused of withholding just such care in practice during a measles epidemic among Amazonian Indians (Tierney 2000). Significantly, Neel left western bodies unmarked, either to scientific investigation or the political economy of power that makes for food scarcity and abundance. However, Neel presciently pointed to the potential biovalue of the diabetic genotype by centering on the genotypical *Other* as the biological pool of outstanding genetic material for collection. And significantly, the research value of the Others' genotype augurs potential commercial value for treating western globalized diabetics.

Neel did not mention the bioethics of collecting this genetic material, or the biopolitics of its conduct and internal application in diverse, multi-ethnic societies. Yet, caloric restriction and increased physical activity go unmentioned in his brief discussion of treatment solutions to the westernized diabetic body. However, to his credit, Neel's "Eugenic Considerations" attributed dual bioprotective and biohazardous properties to the gene based on environmental and historical

specificities. These "considerations" figure prominently in later dissertation chapters. Therefore, in questioning both Neel's original notion of recently sedentised former hunter gatherers being more susceptible to diabetes and subsequent racial interpretations of diabetic susceptibility, I argue for the universality of the "thrifty gene." In arguing for its universality, I seek to make it moot in considering Type 2 diabetic risk.

While the history of diabetes science often approaches its objects of study from triumphant narrative and chronological perspectives, I argue in this dissertation both *against and for* Neel's "thrifty gene" hypothesis. *Against*, buttressed by anthropological assertions that race has no biological basis, and *for* in that obesity and Type 2 diabetes represent the contemporary condition of metabolic possibility, or risk, *irrespective* of "race" or ethnicity—wherever technology and material abundance permit sedentary living in high caloric environments. Further, I must point out that Neel's argument became part of larger, more recent twentieth century conversations about risk and disease, between prediction and diagnosis, with race forming a signal subtext within the scientific narrative.

Over a decade earlier before Neel's article, The Framingham Study began to examine arteriosclerosis, hypertension and other the risk factors for heart disease amongst a select group of individuals in Framingham, Massachusetts. While recognizing the desirability of including a more geographically and demographically diverse research population, the study's designers felt that a small town of between twenty-five and fifty thousand residents would more than adequately provide the six thousand adults needed to initiate the research project. In the original article describing the study's rationale, the researchers believed that a smaller geographic area would make the project more manageable, and the high social capital of the area would make it more efficient in terms of "securing cooperation" (Dawber, Meadors, Felix 1951: 281). However, the authors argued,

> There is, however, reasonable basis for the belief that the distribution of arteriosclerosis and hypertension in the White race in the United States is such that within-community variance is very much greater than between-community variance, and a wide range of type-situations influencing development of these diseases may be found in any community. This hypothesis can only be tested, of course, by similar studies in other communities. (Dawber, Meadors, and Felix 1951: 281)

While in principle the Framingham Study researchers valued participatory inclusion on the one hand, cultural and racial homogeneity were seen as conducive to doing good science, on the other. It must be remembered that in 1951 the Civil Rights Movement had not yet taken flight. The politics of inclusion were still more than a decade away, while the ethics of research inclusion was a longer-term project, as Tuskegee and other experiments continued on.

Yet, the Framingham scientists' quote hints at two important points. First, the argument that greater diversity exists within groups than between groups was, in 1951, conceptually ahead of anthropological notions of difference at the time. Second, in arguing for greater in-group diversity, the quote presages the metabolic contingency Neel would later pose in this thrifty gene hypothesis, which, as I read it, asserted a biological metabolic contingency, not a racial metabolic contingency. I make this interpretation of Neel despite his possible intention in making his hypothesis. In short, neither presumed correlations between race and metabolic disease risk,

nor race and biology. However, both imagined populations of environmental difference, but not of disparity. That said, both the Framingham researchers and Neel were careful not to reify race in formulating and articulating an explanatory language of obesity, Type 2 diabetes, and cardiometabolic risk.

Second, the Framingham researchers marked the White, middle-class citizen as the universal research subject most amenable to universal scientific rationality. What did go unmarked was the categorical construction of *White* in the research imagination and the conceptual and methodological implications such crude categorical efforts would have on the organization of other "races" within the inclusive research future the authors urged. While aware of the flaws and limitations of this categorical approach, they nevertheless encouraged future research amongst diverse populations. Moreover, implicit in the selection of the Framingham Study site and participants was the question of environment as an aesthetically desirable research variable in examining populations stratified by education, class and geography, cross-cut by socialized gender and racial constructs. The intersectionality among these different elemental constructs have gained in research valence, and this dissertation argues, market valence, since 1951.

I present the Framingham Study in this dissertation for two significant reasons. First, it marked the initial research foray into the science of establishing measurable biomarkers for predicting risk occurrence in arteriosclerosis, heart disease, and hypertension, part of what later became part of what is now called the cardiometabolic syndrome. Second, as Type 2 diabetes is now a recognized component of the cardiometabolic constellation, Framingham serves as the conceptual and methodological antecedent which further contextualizes Neel's later argument.

Moreover, Type 2 diabetics are prone to developing heart disease and kidney disease, arteriosclerosis, and hypertension, and inversely, people with cardiometabolic disorders have higher chances of developing Type 2 diabetes. Yet, both Framingham and the Neel's work have since become seen through racial and other lenses, with measured risk ascribed and attributed to these categorically assembled populations. However, the Framingham researchers in 1951 presciently defined and included cardiometabolic illnessness as *epidemic*, an ascription which today has been extended to obesity and Type 2 diabetes (1951:279). I must attest to the number of individuals interviewed, of varying backgrounds and classes, who denied that obesity or Type 2 diabetes could be considered epidemic (or for that matter, endemic or pandemic[19]). The ascription *epidemic,* however, tellingly implies no racial causality or selective risk.

In foregrounding the conceptual era within which Neel's hypothesis arose, I would like to next contextualize contemporary understandings of diabetes through a narrative chronology of the illness over the last century. In this chapter, I begin with the example of *prediabetes*, charting its development from a risk category to a disease category or from a *bio-assessment* to a *biomarker* and the therapeutic rationales organized around this new classification. I situate these developments within the nosological classificatory schema of this period—and the attendant rise

[19] Epidemics (*over* the *demos* or people) are characterized by an illness or disease occurrence characterized by its movement across geographic space through various demographic groups. *Endemic* (*within* the *demos*) is defined as an illness or disease, originating and occurring within a specific place, *sui generis*, a reproducible pathological manifestation in geographic isolation. *Pandemic* (*across* the demos) is defined as an illness or disease originating and occurring within multiple locales simultaneously. I argue in this dissertation that obesity, Type 2 diabetes, and other cardiometabolic disorders are today, epidemic, endemic, and pandemic.

in biomedical professional specialization, market influence, and technological change in discursively reconfiguring the *nature* of the illness itself.

As risk must be assessed before it can be marked, I bring attention to the technologies of assessing and marking Type 2 futures in making my larger argument whereby populations of risk become first defined and later considered valuable for the inclusive purposes of developing next generation diagnostic and risk prediction technologies. I have shown that while race and ethnicity did not figure prominently in early diabetes biomedical and biotechnological science, these categories have increased in research valence over the last fifty years since Neel's *oeuvre*.

Therefore in terms of the broader dissertation, this chapter presents the science to foreground the subsequent ethnographic narrative of the social field in later chapters. I begin here with a narrative history of diabetic risk; numerical interpretations of these risks, the development of increasingly portable technologies of blood glucose measurement, and how Neel's racialized risk populations remain indispensable to these technological developments. I take none of these categories (race, prediabetes, and risk) for granted as I seek to show how they have been discursively circulated by researchers, medical, public health and community groups, as well as patients and populations themselves. These three categories, *race, prediabetes, and risk*, I argue, must be defined by their instability rather than the assumption of any steady classificatory state.

Type 2 Diabetes: A Brief History

Diabetes as an illness has been recognized for over four millennia in various medical systems and cultures, from ancient Egypt, to classical India, China, Greece, and Rome. Known in Sanskrit as *Madhumedha*, it shares the same descriptive diagnostic nomenclature as its Latin counterpart, *Diabetes Mellitus*: Sweet urine. To be more precise, both *madhu* and *mel* mean *honey* in their respective languages. One diagnostic test in classical India for example, was conducted by pouring the patient's urine on the ground near an ant colony—if the ants swarmed the urine, the patient was confirmed diabetic. It should be noted that by the third century BCE, classical Ayurvedic medicine in India recognized over 20 different types of diabetes. Both medical systems diagnostically located the kidney as the organ of affect and therapeutic attention in diabetes.

The discovery of insulin and its physiological role in (1923) led to what has become the contemporary view that impaired pancreatic function determines the development of diabetes. Nevertheless, in the West, the kidney, too, remained the organ of evaluative attention well into the 20th century. Clinically, the diagnosis and monitoring of diabetes was performed through urinalysis until the late 1970s. This method of biological assessment was conducted to monitor hyperglycemia (high blood glucose) to address diabetes *symptoms* and complications; polyuria (excessive urination), nocturia (excessive night time urination), and polydipsia (excessive thirst). At this point in time in the 1970s, glycemic control was not a therapeutic goal—clinically or pharmaceutically.

Type 2 diabetes was formerly known as *adult-onset diabetes*. An earlier iteration was named *Diabetes mellitus*. Type I diabetes was once referred to as *juvenile diabetes* and earlier, as *Diabetes insipidus*. However, over the last 20 years, changes in diet and lifestyle have had the effect of manifesting adult-onset diabetes in children. Also, better understanding of juvenile-onset diabetes as an autoimmune disease (whereby viral antibodies attack the pancreas) capable of afflicting individuals of any age has resulted in the clinical reclassification of both illnesses to Type I and 2 diabetes, respectively. Clinicians I've interviewed have diagnosed 'adult-onset'

(Type 2 diabetes) in three year old children and 'juvenile-onset' (or Type I diabetes) in seventy year old adults. These would have been considered medical anomalies fifty years ago. Today they are disconcertingly unremarkable, both in terms of occurrence and comment.

It is rather unfortunate that T1 and Type 2 diabetes are both referred to and known as forms of diabetes given that they have entirely different etiologies and consequences. T1D is the result of an acute viral infection of unknown origin attacking the pancreas and rendering the organ physiologically dysfunctional. Generally speaking, T1 diabetics tend toward low bodyweight; while obesity figures prominently in both the manifestation and amelioration of Type 2 diabetes. However, the T1D patient requires insulin for the rest of their lives. T1D, therefore, is characterized by both its sudden onset and immediate need for insulin. As such, it is also known as *insulin-dependent diabetes*.

What the T1D and Type 2 diabetes patient do have in common is the use of blood glucose measurement technologies. However, the T1D patient, who not only requires insulin to live and also tends toward catabolism, or decreasing bodyweight over time, needs more continuous monitoring. Increasingly, T1 diabetics wear continuous glucose monitoring devices on waistbands inside their clothes, which set off alarms whenever blood sugars rise too high or fall too low. Some contain insulin pumps that inject insulin into the abdomen of the patient in response to high blood glucose levels at any given time. Others have preset alarms that set off when blood glucose levels either rise or fall beyond acceptable parameters. The use of continuous glucose monitoring devices and insulin pumps by Type I diabetics depend on aesthetics, functional preferences, and affordability. There is a wide price range among this class of blood glucose monitoring devices.

A diabetes educator with T1D whom I interviewed unabashedly showed the continuous glucose monitor taped to her abdomen. Her monitor was equipped with an alarm system that both notified her of the blood glucose excess or deficiency. If in excess, an appropriate dose of insulin is automatically injected into her abdomen; if deficient, she knows to eat a snack with adequate forms of carbohydrate, such as fruit, or better fruit juice, which will be quickly absorbed into the bloodstream. "I wear it 24/7. The thing is, I'm lucky—an insulin pump can cost upwards of nine thousand dollars. If you are on either Medicare or MediCal, you can only obtain a pump if you are able to prove that your pancreas is dead." Therefore in terms of sheer technological and economic disparity, Type I diabetics span a much longer continuum of inequality than do Type 2 diabetics.

Type 2 diabetes, classified into over a hundred types, is a metabolic disorder caused by chronically high levels of blood sugar produced by excess caloric intake and lack of physical activity. Type 2 diabetics comprise upwards of 95% of the entire diabetic population. Type 2 diabetes is amenable to diet and exercise; however, if chronic hyperglycemia is uncontrolled, pharmaceutical interventions along with diet and exercise modifications are attempted. In contrast with T1D, Type 2 diabetes is a slow, progressive illness. However, both illnesses can produce multi-organ and systemic pathologies either originating from or exacerbated by chronically elevated blood glucose levels.

While the mechanism remains unclear, in Type 2 diabetes the body still produces insulin, which somehow cannot enter cells and digest glucose. Therefore, Type 2 diabetes is sometimes referred to as *non-insulin-dependent diabetes*. Implicit here is that, unlike in Type 1 diabetes, having Type 2 diabetes does not mean that the pancreas is biologically or physiologically "dead." It remains in most cases an organ of regenerative possibility until regeneration becomes no longer possible. At this point, the Type 2 diabetic becomes insulin-dependent much like the

Type 1 diabetic. Undigested glucose remains in the bloodstream, from whence it begins adhering to blood vessels, nerve endings, and internal organs. Therefore, the more body fat accumulated, the more insulin resistant the individual becomes. Nevertheless, exercise has been demonstrated to draw excess glucose from the blood into the cells, enabling the digestion of glucose (glycolysis) by improving the bioavailability of insulin. If this is truly *non-insulin-dependent* diabetes, then one would think that increased exercise and improved dietary intake should make both a rational and a practical difference. However, knowledge and practice take on different social forms, even amongst medical professionals charged with implementing and providing Type 2 diabetes care.

<u>On Technologies and Testing:</u>

The Emergence of the Mobile Medical Gaze

Michel Foucault (1973) traced the genealogy of medical attention from its eighteenth century locus, examining the spatial and temporal confluences that changed how illness, disease, and the patient would be viewed by medical practitioners. Illness and sickness formerly apprehended upon notions of individual affliction, as well as descriptive, normative, and relative discourses of frequency and what was "usual," originally existed within the social space of the family. The family, primary source of illness management and surveillance of the sick body was supplanted by clinical supervision and empirical study of the sick body.

Knowledge came from and claims were made by observing many different types of illnesses, parsed out under the name *diseases*, a process that required a separation from the patient from the physician socially, as well as the disease from the patient herself. Inspired by Linnaeus's taxonomic classificatory schemes, disease nomenclature began in the eighteenth century. Diseases, like plants, became nominally ordered and categorized. They no longer had an amorphous, intangible *essence* (i.e. astrological, humoral), but a physiological locus which enabled a materially-descriptive, or empirical, diagnosis.

This new *anatomo-clinical* medicine shifted the locus of medical interaction from the social space of the family home toward the clinic, and its social focus shifted from the family/patient dyad to the doctor/patient one. Thus, the social gaze became the medical gaze; advantageously, government(s) found a new means of surveillance and management of bodies through nascent public health institutional practices.

Arguably this shift from the home to the clinic, from the domestic institution to the medical institution, from the personal to the impersonal, emerged with the rise of both the Industrial Revolution and movement from rural to urban areas. The current rising prevalence in Type 2 diabetes in the developing world follows this nearly two century pattern of urbanization followed by negative nutritional outcomes with obesogenic and diabetogenic[20] consequences. The theoretical viability of Mintz's model locating the deleterious health outcomes resulting from increased urbanization, sugar consumption, and new forms of bodily discipline in relationship to capital still has analytical traction in terms of Type 2 diabetes. This section looks at the development of diabetes diagnostic technologies that monitor, or gaze at the metabolic state of the diabetic body.

Blood glucose monitoring technology, once confined to the physician's office, today is a portable component of contemporary diabetic life; which tomorrow, may exist in the form of a

[20] I use the terms *obesogenic* and *diabetogenic* in terms of *genesis*, not *genetics*. Although much research has been and continues to occur in this area, I suggest no presumptive connection between obesity, T2DM, and genetics.

continuous glucose monitoring device implanted above the sternum. However, while the forms these devices take continue to change, their function(ality) remains contested, imperfect, and imprecise. In addition, the interpretation of the numbers they produce amongst both the professional and lay Type 2 diabetes public, continue to drive the redefinition of the illness as well as the patient.

There are currently three main diabetes diagnostic technologies in clinical use:

1) The Hemoglobin (Hg) A1C Test reflects serum glucose metabolism over the life of a red blood cell, which is roughly three months. It measures the fraction of metabolized glucose in the hemoglobin. This is known as *glycated* hemoglobin. The normal range for non-diabetics is between 4.2-6.0%. Diabetes is diagnosed for those above 7.0%. *Prediabetes* is reckoned within a liminal diagnostic space of 6.0-7.0%.

2) The Oral Glucose Tolerance Test (OGTT) measures overnight fasting blood glucose levels and is usually taken in the morning: Diabetes diagnostic benchmark <125mg/dl.
Prediabetes is estimated as: an impaired fasting glucose level between 110-125 mg/dl, which is equivalent to 6.0% in the HgA1C Test.

The OGTT is considered slightly more reliable than the HgA1C Test due to the fact that during fasting, glucose in the stored form of glycogen is released from the liver into the blood stream. This is known as the *dawn effect* or *dawn phenomenon*. The dawn effect provides a glucose-rich fasting environment for the OGTT to detect insulin resistance. The OGTT's precise reliability, therefore, is due to its overnight assessment of blood glucose metabolism. But in terms of diagnostic advantage, the HgA1C is considered superior as it measures glucose metabolism over the nearly three month lifespan of a red blood cell. Further, the OGTT is a clinically based laboratory test, while the HgA1C has the added advantage of being a portable device that can be taken into the field.

3) Blood glucose meters (widely known as *glucometers*; commonly referred to as *meters*), used by diabetics to monitor their own blood glucose levels, are also employed in diagnosing diabetes. This deployment is usually reserved for initial assessments: in hospital emergency wards; community classes and workshops; as well as public health screenings. These initial assessments using blood glucometers serve the purpose of detecting individuals with elevated blood glucose levels who can next be referred to the appropriate health care provider. There, she will undergo either the Hemoglobin A1C Test, or the OGTT.

Moreover, Bayer has recently developed a portable HgA1C kit for patient self-testing at home. Both clinical and portable tests are considered reliable Type 2 diabetes diagnostic instruments. Yet with the introduction of a domestic self-testing kit, the HgA1C test's applicability now extends from simple diagnostics to more complex and subjectively ambiguous interpretive areas of self-surveillance, and self-monitoring.

In July 2009, the American Diabetes Association's Expert Committee issued a position statement concerning the HgA1C and OGTT's comparative accuracy and reliability in diagnosing diabetes.

The committee cited the HgA1C test's advantage over the OGTT as:

1) Providing a better index of overall glycemic exposure and risk for long term complications;
2) No need for fasting or timed samples;
3) Substantially less pre-analytic instability;
4) Relatively unaffected by acute (e.g., stress or illness related) perturbations affecting blood glucose levels, and;
5) Used to guide diabetes management and adjust therapy.

Further, the expert committee recommended setting the diagnostic threshold for diabetes at 6.5%, the level at which elevated blood glucose begins to produce microvascular pathological changes in the retinal structure of the eye (2009:1329). In effect, the sequelae of retinopathy leading to glaucoma constitute one sign of chronically elevated hyperglycemia.

Do the Eyes Have it?

Interestingly, while undergoing a routine eye examination at the University of California, Berkeley School of Optometry, I was asked by the chief ophthalmologist about my dissertation research project. Having just returned from New York after summer and fall 2009 fieldwork, I desperately needed a fresh set of lenses from which to see through the next phase of my project. When I responded that I was interested in the interplay between Type 2 diabetic risk and technology, he asked if I had heard of the Los Angeles *Latino* Eye Study.[21] Answering in the negative, he confided that eye examinations at the center have been uncovering a surprising number of cases of prediabetic retinopathy among *Latino* students, staff, and faculty associated with the university.

In contrast with the ADA Expert Committee's recommendation of a 6.5% diabetic diagnostic threshold, the LA *Latino* Eye Study noted initial retinal pathology occurring in individuals with HgA1C readings of 6.0%. While this dissertation concerns itself mainly with emergent predictive and diagnostic technologies specifically geared toward evaluating diabetes itself, older retinal diagnostic technologies are now imbricated in the newer interpretive and classificatory schematics of Type 2 diabetes populations at risk.

I find problematic sweeping generalizations that call into question racial categorization as a reliable biological descriptor and index of risk. In the *Latino* Eye Study final report, the term "*Latino*" was used in making claims about "*Latino*" rates of diabetic retinopathy, despite the fact that all the *Latinos* in the study were "mainly of Mexican descent" living in La Puente, California. Nevertheless, the report repeatedly poses *Latino* risk numbers in comparison with *White* risk numbers, which I argue further reinscribes race and risk through the discursive and scientific use of poorly defined, almost arbitrarily viewed, categories *of people*. While tangentially instructive, I suggest that the LA *Latino* Eye Study's primary value resides in understanding and addressing the needs of the community in La Puente as well as wider Mexican/American/Chicano diasporic and transnational communities. Such research, I posit, will expose more socioeconomic, psychological, and other environmental factors at play than any inherently biological fault lines in the seismic study of diabetes.

Although intense debate remains in clinical circles as to what the diagnostic threshold should be, confusion also remains as to what HgA1C level constitutes successful therapeutic blood glucose *control* in existing diabetics. Most clinicians and diabetes educators see an HgA1C reading of >7.0% as a successful target blood glucose control. However, both the ADA's Expert Committee's 6.5% recommended diagnostic threshold and the new retinoscopic technologies detecting prediabetic retinopathy in individuals with HgA1C readings as low as 6.0%, highlight the interplay between technology and interpretation. Paradoxically, intensive pharmaceutical treatment of those between 6.0-7.0% resulted in increased risk of mortality (NEJM June 12, 2008).

[21] McKean-Cowdin, Varma, Hays et al., "Longitudinal Changes in Visual Acuity and Health-related Quality of Life: The Los Angeles Latino Eye Study". *Ophthalmology*, 2010, Article in Press.

A Portable Gaze

What the blood glucometer offers that the other two tests haven't until recently is its portability. Yet while a portable HgA1C Test has been developed, its utility remains as a Type 2 diabetes diagnostic instrument, not a daily monitor or surveillance tool, which the blood glucometer does somewhat reliably. Moreover, there currently exist glucometers on the market capable of storing weeks of blood glucose reading data which can be transmitted to the physician or clinician's office.

Aesthetically, in terms of design, the blood glucometer is beginning to rival the mobile phone. Form and function as both personal aesthetic and reflected biological gaze are now possible through daily engagement with one's *meter* in ways not possible with either the OGTT or HgA1C tests. Meters now come in a variety of colors, tones, and shades. Some glucometers speak, allowing the blind to audibly obtain their blood glucose levels. As an accoutrement, meters can be made to mix and match with your cell phone, clothing, handbag, gloves, nail polish, and shoes.

At a diabetes class in New York, an attendee excitedly showed me an advertisement in a diabetes patient magazine for a stylish glucometer that came in a dozen vibrant colors. "I really want this one," she said, pointing to a neon yellow glucometer, "but I know my doctor would say no because I just got a new one. But I don't care, I just love these colors." In the economics of the glucometer market, the device itself is covered by most insurance plans, either fully or with a small co-payment. The profit comes with the purchase of the disposable testing strips the glucometer requires. The average diabetes patient can spend upwards of seven hundred dollars per year on testing strips alone.

New glucometer technology currently under development intends to produce a device that does not require testing strips, saving the patient both the inconvenience and potential stigma of self-testing in public. Further, this new technology offers alternate site testing, the ability to test on the arms or legs. The conventional way of testing by fingertip prick occurs at a site replete with numerous nerve endings, making testing, especially repeated testing, painful and uncomfortable for some patients.

Several Silicon Valley venture capital managers I interviewed opined that alternate site testing is the future of diabetes self-testing technologies. However, the extant economic conditions from 2008-2010 have made it difficult for companies to obtain the capital necessary to bring alternate site testing technologies to market. This further complicates any company's efforts to develop these technologies. These managers said that no one funding source is willing or able to finance such a project alone.

The centrality of glucometer testing in the daily self-management of diabetes requires constant vigilance. Repeated glucometer testing, interpreting, and taking appropriate therapeutic action can take a toll on diabetes patients.

Joseph, a diabetes patient working with Darlene said,

> There are days when I don't want to be reminded that I am a diabetic. Having to test myself and knowing that I have to keep doing this to stay healthy is hard to keep up, but I'm getting better at it. But the whole thing can wear you out sometimes. It is never far from my mind, even when I try not to think about it. I guess that's a good thing.

Although alternate site testing promises less painful testing experiences, the *pain* of diabetes self-testing, both physical and psychological, will not entirely disappear. We are still a ways removed from the development of painless blood glucose self-testing technologies. We are even further removed from BG self-testing technologies of welcome anticipation like a text, email message or even Twitter tweet: Technologies that would prompt Joseph to think even more about his diabetes without wearing him out.

The Art of Precision

The marketing of glucometer and other diabetes diagnostic technologies have been advertised based on features such as degree of painlessness, amount of blood sample drawn, speed of test result, quality and quantity of testing strips, and as related earlier, aesthetically desirable design and function. I cannot but describe these as true technological innovations within the cultures of diabetes understanding and practice that they circulate. For example, the decrease in length and width of the average diabetes testing needle over the last twenty years has been nothing short of remarkable. However, beyond the technologies of pain and pleasure, specimen and speed, artefact and aesthetics exists the unmarked but presumable purpose of glucometer testing—technological accuracy.

Technological accuracy in glucometer device technology remains elusive, despite undeniable advances over the last two decades. In fact, any particular blood glucose reading may be either ten mmol/L higher or lower than the actual glucometer reading. A prediabetic reading may actually be normal, a high normal reading prediabetic, or borderline low blood sugar reading may actually be normal, etc. The more disconcertingly dangerous scenario would occur when a device consistently registers borderline normal readings on the low end, when in fact the patient had been chronically hypoglycemic (Kost, Tran, Louie et al. 2010: 448-450).

I found it noteworthy over the course of this research that, glucometer advertisements made no mention of the reliable accuracy of their instrument, either broadly in terms of previous technologies, or specifically in comparison with other glucometers then on the market. The majority of clinical outreach and diabetes patient education efforts I participated in emphasized the importance of testing to the exclusion of any instructive discussion about the built-in imprecision of the glucometer itself. The three (UCSF, Alameda County Department of Public Health, and Center for Clinical Research) programs that did go into detail about glucometer reading variability all assigned patients the individual tasks of testing more often to get a sense of what the readings show over time, comparing these with HgA1C tests taken every three months, and talking with their physicians about the specifics of their individual cases.
"There is nothing precise about this," One clinician said,

> It's both art and science. Although we know the diagnostic boundaries of diabetes, it doesn't mean that the same numbers are going to affect the same people in the same way. Or that people will get the same numbers using different glucometers. So even if glucometers were perfect, we would still have this issue.

Nevertheless I must argue that technologically indeterminate readings of normalcy and pathology, between non-diabetic and diabetic, become further complicated when the very classificatory boundaries of health and disease are themselves quite ambiguous, as in the case of

prediabetes. The next section examines the developmental history of prediabetes, first as a bio-assessment and later as a biomarker in the hoary science of diabetic risk.

Prediabetes: from Classificatory Ambiguity to Diagnostic Certainty

In 2001, The Biomarkers Working Group at the National Institutes of Health (NIH) defined a *biomarker* as "a biological molecule found in blood, other bodily fluids, or tissue which represents a sign of a normal or abnormal process or of a condition or disease. A biomarker may be used to see how well the body responds to a treatment for a disease or condition."[23] Insulin response, body mass (BMI, blood pressure are examples of biomarkers. *Race*, for example, is not a biomarker, at least medically.

The above definition leave out so leaves room to imagine boundaries and boundary politics between *normal* and *abnormal*, between *condition* and *disease*, as well of *process* itself and their signs. Such is the case with *prediabetes*. Prediabetes is a technologically ascertainable, yet subjectively asymptomatic index of Type 2 diabetic risk. Approximately seventy-nine million prediabetics currently exist in the US alone. Inclusive of diabetics, over forty percent of these individuals are undiagnosed (Cowie, Rust, and Ford 2008).

However, the rough diagnostic boundaries determinant of what can be considered *prediabetes* remains elusive. I say "rough diagnostic boundaries" because although technological advances have allowed a certain imprecise accuracy in measuring blood glucose levels, the matter of interpretation, alluded to earlier, remains central to this discussion. Prediabetes, it can be said, is based on "arbitrary" diagnostic values due to its very intermediacy (Aroda and Ratner 2008:3259). New diabetes risk prediction technologies on the other hand, relocate "prediabetic" intermediacy within predictive spaces of possibility and pre-diagnostic recognition among the asymptomatic, enrolling potential 'patients' and consumers within new dual conversational identities of risk and responsibility.

Shifting diagnostic categories and disease signifiers have long preoccupied philosophers, astrologers, and physicians. Prediabetes is no exception. As this section explores, not only have the classificatory boundaries collapsed, but *protodiabetes*-cum-*prediabetes* today exists as a debated single disease category requiring pharmaceutical intervention. Discourses concerning Type 2 diabetes predictive risk, prediabetes, and the technologies which enable their measurement exist within a larger medical history.

In the mid-1970s, there began to surface in the medical literature studies linking obesity, glucose tolerance, and insulin response under the clinical term *protodiabetes*. Protodiabetes was characterized as a condition in which obese individuals' adipose or fat cells demonstrated impaired insulin response. Moreover, obese persons with normal carbohydrate tolerance (CHT) were shown to have decreased biological activity of adipocytes (fat cells) in response to insulin (Schulz, Knospe, Michaelis et al. 1978:171).

The origins of protodiabetes classificatory research began primarily in Eastern Europe. In 1974, the VII Karlsburg Symposium on Diabetes Problems was held. The symposium drew 143 scientists from Austria, Belgium, Bulgaria, Czechoslovakia, the former Federal Republic of Germany (West Germany), Hungary, Poland, the former Soviet Union, Sweden, Switzerland,

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[23] *Biomarkers and Surrogate Endpoints: Preferred Definitions and Conceptual Framework*. Biomarkers Definitions Working Group. National Institutes of Health Director's Initiative on Biomarkers and Surrogate Endpoints. Clin Pharmacol Ther, 69 (2001), pp. 89–95. *Cf*: National Institutes of Health. *National Cancer Institute Dictionary of Cancer Terms*. http://www.cancer.gov/dictionary?CdrID=45618. *Accessed*: April 16, 2012.

and the former German Democratic Republic (East Germany). The symposium was entitled "Early Diabetes—Pathogenesis, Diagnosis, Prevention" (Poland 1975:247)[24].

At the time, the protodiabetic was seen as an individual, usually obese, who demonstrated impaired fasting glucose levels and reduced insulin response in the absence of diabetes (Czyzyk, *in* Poland 1975). At that time, the prediabetic on the other hand, was classified as someone who not only had impaired fasting glucose levels and reduced insulin response, but who also had impaired pancreatic beta-cell and liver functioning (Luft, *In* Poland 1975). More significantly, as early as 1972, research began to show a strong correlation between weight loss and improved insulin response in the protodiabetic (Laube and Pfeiffer 1972: 1288-91). Although the term *prediabetes* had been used since the 1960s, it was seen as quite inexact: *potential*, *latent*, and *early* diabetics were seen as better descriptors of what were considered very complex physiological processes.[25]

This protodiabetes research stood in contrast with Neel, who had earlier stated that obesity alone was not predictive of diabetes manifestation, but that obesity and genotype together determined the development of the disease. However, this early protodiabetes research demonstrated the malleability of protodiabetes both as an illness category and a physiological contingency in the face of improved diet and lifestyle changes and resultant weight loss. Today, *prediabetes* has been classified according to what Czyzyk formerly termed *protodiabetes*. In effect, the goal posts have shifted. As a result of an interpretive shift, therefore, protodiabetes as a physiological descriptor gave way to prediabetes as a diagnostic marker, creating productive ambiguity running along a discursive continuum from prevention to treatment. What was formerly a bio-assessment morphed into a biomarker. Discourses of prevention and treatment enabled by the indeterminate diagnostic classification of prediabetes in all its ambiguity made space for the rational medicalization of prediabetes.

Today, early and aggressive pharmaceutical intervention in the treatment of both Type 2 diabetes and prediabetes itself are increasingly being recommended (Vinik 2007; Benjamin, Valdez, Geiss et al. 2000). In fact, there are now calls to consider prediabetes as a stand-alone disease classification requiring immediate pharmaceutical intervention. The medical history of diabetes during the twentieth century can be profitably examined through the development of pharmaceuticals designed to treat the disease. Of particular interest are the ways in which the clinical gaze became aligned with pharmaceutical company visions—and how both (re)informed the changing nosological (classificatory) categories of diabetes. Further, these changing disease categories are shown to have expanded through both market logic and diabetes diagnostic technological advances (Greene 2007a).

In the field, I heard different views concerning these new interpretations of prediabetes or the new treatment protocols they attempt to rationalize. At a diabetes education class in the Livermore Valley, a prediabetic individual asked "When should I know to begin 'pampering' my liver with Metformin?" Surprisingly, Darlene responded, calling the notion of prediabetes as pathology "a theory." Her recommendation: "(You have to) evaluate your own personal and familial risk for diabetes, then go talk to your doctor about whether your condition necessitates pharmaceutical therapy. You never know, you might just end up bringing them new

[24] Reports from Meetings. *Acta Diabetologica* 12(3-4): 245-249, May 1975.
[25] *See*: Pfeiffer (1969) *Obesity, Hyperinsulinism and Diabetes Mellitus: Facts and Hypotheses.* Proceedings of the Royal Soc. Med. Volume 62 April 1969. *Cf:* Neel (1962: 696-697).

information." The notion of prediabetes as a theory on the one hand and a contingent fact on the other both ring true in the case of Type 2 diabetes risk.

For example, in contrast with Darlene's statement just mentioned, a public health official I interviewed saw things differently. We had been discussing the rationale behind the pharmaceuticalization of prediabetes. Metformin, the most prescribed drug in newly diagnosed cases of Type 2 diabetes, was now being prescribed to prediabetics. Although diet and lifestyle alone have been shown to prevent prediabetic progression to Type 2 diabetes, Darren cited the inability of large numbers of patients to manifest the necessary behavioral shifts required in making therapeutically effective diet and lifestyle changes. Also, contemporary obesity complicates the issue entirely. Therefore, in the case of both diagnosed prediabetes and predicted Type 2 diabetes risk, "We must" in his words, "treat patients within the context of their lives."

Testing Contexts: Diet, Lifestyle, and Metformin

From 1996-1999, The Diabetes Prevention Program (DPP), the most ambitious diabetes research project to date, recruited over 3000 volunteers with impaired glucose tolerance (IGT). In terms of aim, size, scope, and longitudinal continuity, the DPP is the diabetes research equivalent of the Framingham Study. The research volunteers, technically prediabetic, were evaluated and selected primarily by Fasting Oral Glucose Tolerance Test. Involving over 20 medical centers and research teams, the project's four control groups—Metformin, Intensive Lifestyle Modification, Placebo, and Troglitazone—were examined to measure the onset to Type 2 diabetes in these four groups of individuals with impaired glucose tolerance. [26] Essentially an efficacy trial, the DPP was envisioned as providing a basis for more informed prevention and treatment strategies (Diabetes Care 1999: 623-625).

The results of the Diabetes Prevention Program clearly demonstrated the superiority of intensive lifestyle modification (diet, exercise, stress reduction) in preventing the onset of Type 2 diabetes over a longer term (ten year) period than either the Metformin or Placebo group. However, over the shorter term (less than five years), lifestyle change and Metformin were equally effective in preventing T2D onset (1999: 623). Darlene understands the contexts in people's lives that prevent quick adoption of diet and lifestyle modifications in the face of a Type 2 diagnosis, much less prediabetes. Herself a Type 1 diabetic, Darlene adheres to an active fitness program and vegetarian diet.
Nevertheless, as she explained,

> Some physicians and clinicians don't understand why diabetics, and especially prediabetic patients, don't make lifestyle changes faster, in light of the evidence that these changes can make a big difference. They almost see it as a simple self-discipline and self-control issue. A lot of these folks (physicians and clinicians), and I've seen it, are highly disciplined people who developed or already had these habits during their professional education. They can't understand why everybody can't get up at 4:30 every morning and exercise before working a twelve hour day like they do. But these are proactive Type A's who have been successful

[26] The Troglitazone group was disbanded after a research subject suffered liver failure and consequently died post-transplant surgery.

> with most things they've tried. And most of them (physicians and clinicians) don't have diabetes.

While Darlene recognizes the importance of diet and lifestyle, personally and professionally, she was careful in tailoring her diabetes message to her audience. Her comment implied a connection amongst some physicians and clinicians between behavior and success. Self-control as a means of successfully determining desired outcomes comes easier to some than to others and often carries with it moral connotations, something the successful need remember in counseling those they see as lacking in self-discipline and willpower. Yet Darlene's comment further suggests the unique challenges that diabetics face, challenges much different and ultimately more consuming than the life hurdles routinely cleared by diabetes experts and clinicians without diabetes.

The most recent American Diabetes Association Position Paper on Nutrition found exercise to contribute only modestly to weight loss, while improving insulin sensitivity and long term health maintenance. Exercise proved most successful when combined with behavioral modification therapy. However, the authors could find no consistent nutritional guidelines for healthy weight loss; macronutrient requirements have not yet been developed. Interestingly, the authors claim greater success with anti-obesity medication than either diet or exercise in those with Body Mass Indexes (BMI) >27.0. Dietary regimens consistently fell prey to weight regain, while exercise was seen a useful long term strategy, but too slow to make an effective therapeutic intervention in the obese patient either at risk or with Type 2 diabetes (Bantle, et al. 2006:2140-2041; Bantle, et al. 2008).

However, various meta-analyses have been conducted to determine the effectiveness of introduced pharmaceutical interventions in addressing prediabetes. The rationale undergirding these interventions aims at preventing the onset of full blown Type 2 diabetes. I use the word *intervention* here due to clinical uncertainty as to whether introduced pharmaceutical regimens should be considered *treatment* or *prevention*.

A 2004 study previously demonstrated the effectiveness of dietary and lifestyle change over pharmaceutical intervention in delaying Type 2 diabetes onset within a three year period (Leung, Kwan and Evans 2004). Second, it is already known that eighty percent of prediabetics can normalize their blood sugar levels through diet and lifestyle interventions alone and that; Third, Type 2 diabetes patients who meet the American Heart Association's weekly aerobic exercise targets and dietary recommendations can sharply reduce, if not eliminate their dependence on medication (Suitor and Kraak 2007). Lastly, the Physicians Committee for Responsible Medicine argues that Type 2 diabetes pharmaceutical interventions can be eliminated by following a high fiber, complex carbohydrate-based vegan diet (Trapp, Barnard, and Katcher 2010; PCRM Annual Report 2006).

Despite uncertainty as to whether pharmaceutical interventions control blood glucose levels or impede the (inevitable) Type 2 diabetes process, pharmaceutical approaches are being promoted over diet and lifestyle change in the prediabetic individual. Pharmaceutical approaches or pharmaceutical interventions perhaps best term these new prediabetes drug protocols, as the indeterminacy of the illness category raises the question as to whether this constitutes prevention or treatment (Lily and Godwin 2009). Moreover, these marketed pharmaceutical regimes are intricately tied both to the technologies which produce them as well as those clinical technologies which rationalize their prescription. Such is the case with prediabetes. As one public health official related, "For all intents and purposes, prediabetes is now a separate disease

category requiring aggressive intervention. Advances in diagnostic technology have made this determination possible."

However, recent clinical research has shown that pharmaceutical attempts at lowering Hemoglobin A1c to the "prediabetic" control threshold of <7.0% carries its own risks. The purpose of these research efforts was to examine whether pharmaceutically induced intensive blood glucose control had a positive effect on reducing cardiovascular complications and outcomes.

The results were less than impressive.

> Because of ongoing uncertainty regarding whether intensive glycemic control can reduce the increased risk of CVD in people with type 2 diabetes, several large long-term trials were launched in the past decade to compare the effects of intensive and standard glycemic control on CVD outcomes in relatively high-risk participants with established type 2 diabetes. In 2008, two of these trials, Action in Diabetes and Vascular Disease—Preterax and Diamicron Modified Release Controlled Evaluation (ADVANCE) and the Veterans Affairs Diabetes Trial (VADT), were completed and showed no significant reduction in cardiovascular outcomes with intensive glycemic control (Skylar, Bergenstal, Bonow et al. 2009).

Further, another trial, the Action to Control Cardiovascular Risk in Diabetes (ACCORD) was discontinued after the discovery that the project's aggressive pharmaceutical strategy of reducing Hemoglobin A1c levels to <6% resulted in increased mortality among research participants (Ibid: 352). To put this into perspective, the LA *Latino* Eye Study found microvascular pathologies occurring in individuals with an HgA1c level of <6%, well within the normally accepted range of successful blood glucose control of <7%, but below the ADA diabetes diagnostic threshold of 6.5%. These three studies raised questions as to both the role of intensive pharmaceutical blood glucose control as well as the prospects for reducing cardiovascular complications without iatrogenically producing (or drug inducing) said negative cardiovascular outcomes. Ethnicity, HgA1C diagnostic thresholds, and treatment now intersected each other, nuancing notions of universal diagnostic standardization and treatment indications.

As a result of these ambiguous trial findings, three organizations which have historically been less then collaborative, the American Diabetes Association (ADA), the American College of Cardiology (ACC), and the American Heart Association (AHA), decided to reevaluate the clinical recommendations for targeted blood glucose levels for diabetics (Ibid: 352). Realizing that aggressive pharmaceutical blood glucose lowering strategies increased cardiovascular mortality, the three major organizations jointly recommended a comprehensive treatment approach to the entire cardiometabolic constellation of illnesses. Attempting to lower HgA1c levels below 7% was not advised, while recommended diet, lifestyle, aspirin use, etc. comprised elements of a total treatment program (Ibid: 355).

Interestingly, all three trials found that intensive blood glucose control worked best with those who were both younger and had diabetes for a relatively short time (Ibid: 355). Given the curve between when aggressive pharmaceutical intervention proves harmful or beneficial, and the emphasized importance of a comprehensive cardiovascular approach, one begins to see the limits of drug therapy and the necessary potential of diet and lifestyle changes. After all, the

safest way to lower one's blood glucose level is through exercise and diet; the majority of the cardiovascular mortalities in the ACCORD study were due to drug induced (iatrogenic) hypoglycemia (Ibid: 352-353) . It should be noted here that all three studies were drug studies; none had a diet and/or lifestyle component to the attempted blood glucose control research protocol.

Therefore, both the early and late stages of Type 2 diabetes onset arguably respond better to cardiovascular friendly activities, foods, and molecules (such as aspirin) than through a tunnel visioned approach which sees "successful" blood glucose control as the Holy Grail of diabetes therapy and management. Darlene's ambiguity over the science of prediabetes is based on the knowledge that diet and lifestyle changes remain the best long term, sustainable, and healthy way of living with the ambiguities of Type 2 diabetes. The "contexts of people's lives" alluded to earlier makes therapeutic room for those who need that five year window to make necessary life changes before associated cardiometabolic pathologies begin to alter living contexts for the worse. I make these interpretations based on the DPP and its research outcomes predicated upon *control* groups. Such bounded groupings of controlled practices around Type 2 diabetes rarely exist on the ground. It is much messier than that. As an *efficacy* trial, the Diabetes Prevention Program sought to apply the basic science of molecular chemistry and physiological systematics solely within a clinical research setting. However, in terms of real world *effectiveness*, the DPP fell short in terms of enunciating improved therapeutic *efficiency* by making available and circulating new knowledge about both Type 2 diabetes and its treatment.

"Contexts" vary in terms of disparities in access, cultural competency, environmental health and social justice, and medical literacy, among other factors. A crisis in the medical student to physician pipeline further contextualizes and complicates the diabetes treatment landscape in the contemporary United States. In light of the results of the DPP, ACCORD, ADVANCE, and VAT trials, and the arguably belated collaboration between the American Diabetes Association, the American College of Cardiology, and the American Heart Association, the next section aims to tease out the professional and economic factors shaping Type 2 diabetes treatment. I aim to show how the absence of clinical expertise informs the technological rationalization of the illness.

Expertise *Manque*: In the Absence of Experts

I situate this chapter within a discussion of embodied expertise in the form and person of the endocrinologist and the pipeline issues affecting the shortage of physicians in the medical specialty. I suggest that the shortage of endocrinologists, and by extension, medical access, rationalizes technological intervention enabled in two significant ways. First, making the clinical gaze portable in the form of the glucometer and second and in connection, decentering the locus of interpretation from the clinician to the patient.

I begin this section with the epidemiology and future projections in the growth of Type 2 diabetes in the United States. I contrast this with the present shortage of endocrinologists and primary care physicians, which threatens the possible successful therapeutic futures of not only diabetes and the wider cardiometabolic syndrome, but the entire medical system as a whole. I suggest in this section that these shortages in professional medical labor further rationalize technological interventions, shifting the burden of labor from the clinician to the patient.

Currently, one in three persons born in the US today will develop Type 2 diabetes. One in six children in the US is prediabetic; one in three obese children in the US is prediabetic. One in two *Latino* Americans born today will develop Type 2 diabetes. According to the Centers for

Disease Control (CDC) cases of Type 2 diabetes will triple by 2050, affecting one in every three adults in the nation. (CDC, October 22, 2010).[27] Nevertheless, with nearly 26 million diagnosed and 6 million *hidden* or undiagnosed diabetics in the US, fierce competition currently exists among manufacturers for domination of a burgeoning blood glucometer market growing by 1.6 million newly diagnosed Type 2 diabetics each year. Today, expenditures on diabetes comprise seven out of every ten health care dollars.[29]

Further, it must be kept in mind that very few people die from diabetes. The majority of diabetics die from kidney failure or heart disease. Diabetics have a two-to-fourfold increased chance of dying from cardiovascular disease (Skylar, Bergenstal, Bonow et al 2009). It is the microvascular complications and treatments arising from diabetes—permanent nerve damage, retinopathy, poor circulation resulting in limb amputations, decreased kidney functioning necessitating renal dialysis, pharmaceutical drugs, etc.—which drive the increasing cost of diabetes patient care. It is also worth noting that end stage renal disease is the only universally covered illness in American medicine. In other words, many diabetics do not become eligible for medical insurance until these life-threatening complications manifest themselves. This should give pause to consider the economic, medical, ethical, and policy priorities and foci of the various institutions and interests terracing the topography of care of the US diabetic medical landscape.

As of 2008, there was only one board certified pediatric endocrinologist for every 17,000 obese children in the US. Two states, Wyoming and Montana, had no board certified pediatric endocrinologists. Massachusetts had the highest ratio of pediatric endocrinologists to obese children at roughly 1:5,000. Mississippi, the most obese state in the nation, had a ratio of nearly 1:100,000. Interestingly, geography explains little: the availability of endocrinologists does not necessarily correlate to either obesity rates or diabetes prevalence (Dixon 2008). According to Stewart (2008),

> The endocrinologist shortage has impaired access to care by patients with diabetes, obesity, metabolic syndrome, lipid disorders, thyroid nodules, thyroid cancer, osteoporosis, pituitary disease, adrenal disease, menopausal symptoms, and reproductive disorders. It is standard to encounter waits of three to nine months and many endocrinology practices are closed to new patients.[30]

According to Darlene, the three county area of the East Bay of Northern California, with some of the wealthiest communities in the state, has only one board certified endocrinologist in private practice. Santa Cruz County has only one board certified endocrinologist as well, located in North County, while the majority of the *Latino* population resides in South County. In both California and New York I was told by diabetes professionals of the lack of endocrinologists coming down the medical specialty chute. One diabetes educator in San Francisco said that endocrinology isn't "sexy" to young medical students, who seek more lucrative careers in

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[27] CDC Press Release, October 22, 2010. CDC Division of Media Relations. http://www.cdc.gov/media/pressrel/2010/r101022.htm. *Accessed* November 18, 2010.
[29] The Economic Costs of Diabetes for 2007. *American Diabetes Association Statement*. 2007.
[30] Stewart, Andrew. 2008. The US Endocrinology Workforce Shortage: A Supply-Demand Mismatch. *Journal of Clinical Endocrinology and Metabolism* 93:1164-1166.

anesthesiology, cardiology, and surgical specialties, particularly plastic surgery.[31] Cardiologists in private practice are bringing in more endocrinologists to care for an increasing Type 2 diabetes patient load, which then allows cardiologists to concentrate on more economically lucrative medical practices (Stewart 2008: 1164). While more foreign trained endocrinologists are being recruited to fill in the gaps, their numbers are insufficient given the burgeoning Type 2 diabetes population.

However, an internist in San Francisco working with at risk populations added to my professional pipeline question by posing another:

> Yes there is an endocrinologist shortage. Yes there are those who believe that diabetics and the chronically obese should have access to endocrinologists. I wouldn't disagree with that and I have had many discussions with my colleagues on this issue. But I always say (that) the real question is 'what is the best front-line medical specialty for addressing these problems, endocrinology or primary care?'

Dr. Shapiro's point was directed to the even larger pipeline issue in modern medical education, the lack of medical students choosing primary care as a specialty and going into practice. She continued,

> The cost of a medical education today literally forces medical students, even the most altruistic and idealistic, to choose medical specialties which will allow them to pay back their student loans. And this generation is more into show and face. Glamour. I believe this also influences the kind of medicine they choose to practice. Endocrinology and primary care are *not sexy* (*Speaker's* emphasis).

Not sexy. When I told Dr. Shapiro that she wasn't the first person to mention that over the course of my research, she wasn't surprised.

> It's really all about money, power, and sex. It's always been this way. But through all kinds of media people get this message at younger and younger ages. Medicine is no different. Students know it, they want it, (and) they get it.

Therefore in terms of professional prestige and financial reward, endocrinology, primary care, and for that matter, Type 2 diabetes, are not seen as low-hanging golden apples within the desired reach of US medical school graduates and practitioners. The growing Type 2 diabetes and cardiometabolic population, from the perspective of professional labor, requires large numbers of trained physicians willing to address the demand side of this illness phenomenon. It is estimated that there are between seven to ten thousand available endocrinologist positions in the US alone (*Ibid*: 1164).

[31] Further, cosmetic surgery is not reimbursed by health insurance and is usually a straight cash transaction.

Added to the calculus of how expertise is allocated and often rationed throughout the Type 2 diabetic landscape is the emergence of the Certified Diabetes Educator (CDE). Despite the current chronic shortage of CDEs, professional gatekeeping by the American Association of Diabetes Educators reveals the lucrative allure of the diabetes population as a growing market, consumer, and patient entity. Several years ago, the AADE changed its eligibility criteria, restricting certification to nurses, registered dieticians and nutritionists, pharmacists, and physicians. Previously, medical anthropologists (for example) would have qualified to become Certified Diabetes Educators. Paradoxically, and in the face of a growing Type 2 diabetes epidemic, the AADE constricted member eligibility. One could only surmise that this was an act of professional gatekeeping, something several perplexed and overworked CDEs communicated to me.

The CDEs at the Diabetes Teaching Center at the University of California, San Francisco are stretched thin, wearing many hats—as nurses, registered dieticians, clinicians, and pharmacists—in addition to their administrative and diabetes class and workshop planning duties. These professional duties and obligations spread them throughout the UC San Francisco medical complex. In effect, there are not enough Certified Diabetes Educators available to meet growing patient demand for diabetes services, education, and community outreach. One CDE estimated that there are approximately 1.7 Certified Diabetes Educators at UCSF to administer to the needs of the entire diabetes population served by the hospital.

However, Darlene complained of gatekeeping within these understaffed hospitals (she was not referring to UCSF) where she unsuccessfully lobbied to start a diabetes education class. She believes that diabetes centers jealously guard their potential diabetes patients/students, particularly those with private health insurance. Public health CDEs such as her are left to scramble, organizing classes and workshops among the elderly, disenfranchised and uninsured.

I spent one month during the summer of 2010 with Darlene at her diabetes education classes in the San Francisco Bay Area. One day after class, a woman walked up to her, full of worry. "Darlene, my doctor referred me to a diabetes education class at ____Hospital and I just found out that my health insurance was charged nine hundred dollars! I thought the class was free. What can I do?" Darlene recommended she take up the issue with her physician, insurance company, and the hospital. "This happens all too often," Darlene told me later. "Many physicians have no idea whether they are referring their patients to free public diabetes classes or fee based ones."

The shortage of endocrinologists and CDEs points to another phenomenon in the Type 2 diabetic contemporary: a growing gendered division of labor in the delivery of services, education, and treatment. While endocrinologists are predominately male and as physicians can be imagined as a masculine form of embodied expertise, CDEs on the other hand, coming mostly from the ranks of nurses, dieticians, and nutritionists, are overwhelmingly female.[32] I find this instructive in terms of analyzing the gendered role of both expertise and technology.[33]

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[32] With respect to women and gender, pharmacists, also allowed to become CDEs, are represented more equitably in this former male professional bastion. *See* Levy, H.B. 2006. Women in Pharmacy: A Good Match. *Ann Pharmacotherapy* 40: 952-954.

[33] I was told by a nurse that nurses tend to use the word "adherence" and physicians "compliance" when describing the same thing: (un)cooperative patient behavior about prescribed and introduced diet, lifestyle, pharmaceutical, and glucometer regimens. In terms of authority, the horizontal positionality *adherence* evokes contrasts with the top-down vertical authority which *compliance* summons. Cf. Conrad, 1985.

I have suggested in this chapter that in the absence of clinical expertise on the ground, Type 2 diabetes blood glucose self-testing and monitoring technologies and pharmaceutical regimes have risen to the fore. In turn, the moral economy of care has shifted from the physician to the patient, who now must become both interlocutor and interpreter of clinical information. Technology has helped improve controls on serum glucose, while also empowering the patient to take greater responsibility and obtain a better understanding of diabetes as a lived experience. Structural under-capacity within the healthcare system, combined with the health insurance situation, make it imperative that the patient take control of their blood sugar levels by actively and consistently managing their diabetes.

However, ambiguity, whether concerning diabetes classification, the role of lifestyle and pharmaceutical interventions, technological imprecision, missing physicians, or even constructions of race and risk, runs rife through this chapter and into the next. The history of prediabetes and diabetes, originally not premised upon racial or ethnic notions of or correlations with Type 2 diabetes risk or prevalence, increasingly focused on racial theories of risk over the course of the twentieth century (Duster 2007, Fee 2006, Neel 1962).

The following chapter will explore how the research and development plan of a new Type 2 diabetes technology sought to include at-risk minorities one biotechnology company deemed vital for producing both clinical and market value for their instrument. The five and ten year window opened by the Diabetes Prevention Program redrew both the predictive outlines of risk and prognostic contours of therapeutic success. I will next show how this window made room for new technologies of predicting diabetic risk in the asymptomatic individual.

Chapter Three: Inside the Technology of Appearances

"Be able to tell your patients they are at risk for diabetes before their bodies do"
Tethys BioSciences Advertisement

In this chapter I examine a new diabetes technology that claims to predict future diabetes risk in otherwise healthy individuals. However, I will show that extant racial categories and their scientifically imagined members continue to be seen as important research populations of biovalue to both public and private sector researchers. I examine the company's, Tethys BioSciences', attempts to recruit US African Americans to test their new Type 2 diabetes risk prediction technology in the hopes of increasing the clinical and market value of their product. I present an ethnographic narrative of the ethical and translational challenges affecting this company's recruiting efforts. I aim bring into tension the interests seeking to individualize Type 2 diabetic risk through the development of new biotechnologies, in contrast with those high-risk populations seen as indispensable to the research and successful marketing of these technologies.

A Sunday Walk in Oakland

On a beautiful Sunday morning I walked through downtown Oakland on my way to Jack London Square for the local annual Step Out! Walk Against Diabetes event organized by the American Diabetes Association. Minnie, whom I recognized as a Step Out! Volunteer because of her red volunteer t-shirt, and I struck up a conversation as we headed to the event. After telling her about my research she said,

> That's good. We all need to fight against this terrible disease. I know it will kill me one day. Everyone in my family has it (diabetes). I know it's coming for me, too. I might even have it now, but I don't want to know. As you get older, your chances go way up, especially for a middle aged Asian lady with my family history. We have to find a cure.

Arriving at the event site, Minnie and I bade our respective farewells and best wishes and went about our separate ways. At the registration desk, a large group of extremely helpful ADA volunteers were busy checking in registrants, handing out event t-shirts, and accepting envelopes of donations collected by individual and group walkers and their respective sponsors. Walking teams were organized by and comprised of: 1) corporate sponsored teams; 2) institution sponsored teams, and; 3) individuals with; and families, loved ones, and supporters of current and former diabetes patients. Another ADA table furnished breakfast in the form of bagels, coffee, fresh fruit, and orange juice. On the event stage, a DJ played music while doubling as event master of ceremonies. James Brown's "I Feel Good" set the thematic backdrop and tone for the event, "I feel nice, like sugar and spice…."

There was something about the event of which Potemkin would have been proud. The local American Diabetes Association head, an affable, friendly fellow, was busy with the setting up, organizing food, volunteers, etc., while the discursive center of event attention was the main corporate sponsor. Tethys BioSciences was the lead sponsor of the diabetes walk, a fact the DJ never failed to mention at least every ten minutes, or two songs, over the course of an hour and fifteen minutes. In each announcement, he implored the assembled to make sure and visit the Tethys table, "where their representatives are eager and ready to talk to you." Genentech, a major

biotechnology company, as well as the Walgreen's and CVS pharmacy chains were secondary sponsors.[34]

Minnie works as an administrator for one of the two large drugstore chains. During our walk she told me of CVS's recent acquisitions and mergers as it expands across the United States. "They plan to eventually operate around one hundred pharmacies in San Francisco alone. Walgreen's already has seventy-five stores in San Francisco," she said. That works out to around one CVS or Walgreen's drugstore for every fifty residents of the city of San Francisco.[35] [36] "This is a battle for the Type 2 diabetic dollar," Minnie averred. Her comments lent rationality as to why both drugstore chains were present and co-sponsoring the Step Out! Against Diabetes Walk. The battle is apparently on.[37]

I had previously made several unsuccessful attempts to contact Tethys BioSciences to arrange a visit to their research and administrative campus and conduct interviews with both research scientists and company management. Therefore, when I heard that Tethys was a primary sponsor of the Step Out! Against Diabetes Walk, I decided that the event was not to be missed.

As Anna Tsing (2000) wrote,

> (Yet) conjuring is always culturally specific, creating a magic show of peculiar meanings, symbols, and practices. The conjuring aspect of finance interrupts our expectations that finance can and has spread everywhere, for it can only spread as far as its own magic. In its dramatic performances, circulating finance reveals itself as both empowered and limited by its cultural specificity (119).

From James Brown to Potemkin, the Oakland Step Out! Against Diabetes Walk provided a venue for an attempted biotechnological conjuring up of *African American* bodies, empowered

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[34] In 2009, Genentech was acquired by Roche Pharmaceuticals for an estimated $47 billion US dollars. Genentech's focus on genetic, genomic, and postgenomic research coupled with Roche's pharmaceutical heft can be seen as a logical strategy toward bridging the research valley of death. The mapping of the human genome made visible genetic sites, which have sparked pharmaceutical development of *drug targets*, or new molecules designed to target specific genetic/genomic sites, or targets. I make this note in not only invoking the notion of a "research gap," but also in further clarifying the expanded pharmaceutical company presence at and sponsorship of the Step Out! Against Diabetes Walk.

[35] Both Walgreens and CVS have also begun offering in-store primary health care services. See *Health Care in the Express Lane: Retail Clinics Popping Up All Over the Place*. http://www.foxbusiness.com/personal-finance/2011/06/07/health-care-in-express-lane-retail-clinics-popping-up-all-over-place/#ixzz1PGKh7TBr. *Accessed* 6/14/2011.

[36] At a suburban Rochester intersection I was astounded to see a major retail pharmacy chain store on all four corners, less than a half a block away from the glittering, huge new Wegmans Supermarket and Pharmacy I had just left in awe.

[37] The relationship between the two companies has been quite tenuous. While Walgreens is the largest retail drug store chain with the highest revenues, CVS Caremark is a "pharmacy health care provider," administering pharmaceutical programs and services to over 2,000 companies and government agencies representing nearly fifty-three million US citizens. Walgreens recently balked at honoring CVS Caremark clients' prescriptions. Less than four months before the Step Out! Against Diabetes Walk the issue was settled, but not after much mutual recrimination.

by venture capital and limited by its own cultural specificity, in short, a translational disaster, as we shall presently see.[38]

Before the walk began, a Tethys vice-president took to the microphone after a diagnosed Type 2 diabetic tearfully recalled her struggles with the illness. He reiterated Tethys' commitment to fighting diabetes, but immediately followed stating ironically that "There are over fifty-seven million prediabetics in the country and what we want is to develop early detection models that can get people involved earlier in diabetes prevention and treatment." He made no mention of existing diagnosed diabetics such as the preceding speaker, undiagnosed or hidden diabetics, or anything concerning Type 2 diabetes itself. Marketing hat on, he decentered the theme of the day from diagnosed Type 2 diabetes to the risk of developing Type 2 diabetes, which his company proffers to predict. Having shifted the goal from diagnosis to risk prediction, he created discursive room to medicalize this diabetic risk in terms of either prevention or treatment.

I decided to visit the Tethys table and speak to their "eager and ready" representatives. I met the director of marketing development and another of the company vice-presidents, both of whom enthusiastically greeted me. However, as I introduced myself and my research, the vice-president became quite distant and hesitant, leaving the director of marketing development with the task of keeping a bright face in a public place. When I asked about the applicability of the data from the Inter99 Danish cohort onto the diverse US Type 2 diabetic epidemiological map, the director of marketing development informed me that this is precisely why Tethys seeks to conduct trials in the US among high-risk Type 2 diabetes populations.

We exchanged smiles, business cards, and "nice meeting you" courtesies. Seizing the opportunity to personally request a visit to Tethys' headquarters, the marketing development director welcomed me to the Tethys campus. Not a problem, just contact and set it up, which I attempted some days later. No response to either emails or phone calls. My suspicion was piqued, not only about the company but the entire premise of the Step Out! Against Diabetes event.

Something wasn't adding up. In California, Oakland ranks second to Los Angeles in terms of the size of its African American population, yet African American turnout for the diabetes walk was quite low. It appeared as if there were as many volunteers as walkers, and even fewer African Americans. If Tethys was both serious and informed about recruiting African American research participants, much less interest, then why hold a diabetes walk in Oakland on a Sunday morning? If as in Chapter Four I accurately relate the importance of churches in enlisting African American participation in various biomedical efforts, then Sunday morning arguably is not the best time to generate interest in and participation by a targeted at risk community -- James Brown, notwithstanding. The situation brought to light the incommensurability produced within the social field when translational research misses its intended public mark. Even when imagined by the smartest people in the room.

However, inside the technology of appearances there are many mirrors. The biopolitical diabetes risk score of the nation-state usually assigns risk according to the respective population

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[38] I take Tsing's definition of "conjuring" as spirit evocation and magic performance "highlight(ing) the intentionality of the performance, the studied charisma of the performer, and the hope of moving the audience beyond the limits of rational calculation" in application to the case of Tethys attempts to both attract *African Americans* and push the discursive boundaries of diabetic concern from diagnosis to risk prediction (Tsing 2000: 118).

groups within that particular nation-frame. For example, the Australian Diabetes Risk Score assigns high-risk to "Aborigines, Torres Strait Islanders, Maoris and Pacific Islanders." Tethys' PreDx™ Diabetes Risk Score, on the other hand, does not include race as a risk assessment category, using "family history" instead (Urdea, Kolberg, et al. 2009).

Nevertheless, Tethys sought to test the actual instrument on an imagined racial risk group, despite the fact that the company's own study of a *multiethnic* cohort found no risk predictability for Type 2 diabetes attributable by ethnicity (Kolberg, Wagenknecht, Rowe, et al. 2010).[39] I argue that part of the technological innovation the instrument represents is in attempting to hardwire racialized diabetic risk into the software of the PreDx™ Diabetes Risk Score. This innovation rests on the technological subsumation of the overtly racial categories of the biopolitical state by the neoliberal market forces of universal risk which presumably transcend race and parochialism.

I thread this chapter within the larger dissertation argument that risk and race become re-imagined and reconfigured through discourses and methodologies aimed at generating both a confident Type 2 risk prediction model and robust market potential. I provide room for better understanding the challenges facing biotechnology and clinical research efforts to both imagine and successfully communicate with *African American* communities. I argue that while diversity and inclusion (Epstein 2007) have increased the biovalue (El-Haj) of these populations, in this case *African Americans*, a translational wall still exists between research communities and targeted risk groups. My intention is to demonstrate the ways in which these new diagnostic tools reconfigure contemporary understandings of Type 2 diabetes, both as a categorical continuum between risk and disease, and also as a translational research imperative.

In this attempt, I conducted an analysis of the forms of inscription necessary to generate market value, venture capital, as well as claim ownership of facticity, knowledge, and truth. In this chapter, I nominally present "fact," "knowledge," and "truth" as attempted representations, or claims, some more plausibly performed than others, but certainly not as verities. Plausibility and verity notwithstanding, I further contextualize this chapter's discussion within the current translational "Valley of Death" in biomedical research, the chasm between ideas and innovation, or between investment in biotechnology and demonstrable health outcomes.

Emerging diabetes risk prediction technology decentered my original ethnographic attention from diagnosis to that of predictive risk—and the ways in which *risk and speculation* co-constitute each other in the process. More significantly, I was unaware of the intersectional role that race would play in this technological amalgam between risk and speculation. My ethnographic narrative in this chapter animates Anna Tsing's (2000) definition of an "Economy of Appearances," namely, performances animated by venture capital based on imagined future profits. However, these profits must first be extracted through a series of performances "in the limelight of those historical moments when capital seeks creativity rather than stable reproduction" (Tsing 2000: 118).

I present the following example as both a preliminary investigation and invitation to think through the possible implications of newly emergent Type 2 diabetes technologies, the stakes involved concerning their marketed diffusion, and the forms of racial inclusion which different

[39] While *race* continues to serve as a descriptive and operational population category in some US national research circles, *ethnicity* has become the operational descriptor of categorical choice in Europe (Annemarie Mol, *private communication*). Neither term, however, obviates or explicates assumptions of essentialized biological difference between ascribed, inscribed, and imagined phenotypical communities.

stakeholders desire. *The technology of appearances*, therefore, is twofold: 1. The ways in which innovative research technologies must *appear* to venture capital, and; 2. The ways in which *phenotypical appearance*, or racial categorization, figures into the production of these diabetes technologies.

Unveiling the Future

At the annual meeting of the American Diabetes Association[40] in June 2009, San Francisco Bay Area Tethys BioSciences announced its development of a new test for Type 2 diabetes based on a prospective study of nearly 7,000 individuals in the Inter99 cohort, a population-based primary prevention study of cardiovascular disease in Denmark. What distinguishes this new cardiometabolic assessment technology from previous iterations is that it tests for Type 2 diabetes risk, *a priori*, not clinical diabetes itself, *post facto*, nor its clinically ascertainable precursor, prediabetes, *inter alia*. Further, this new diagnostic tool, called the PreDx™ Diabetes Risk Score (DRS), claims to predict one's chances of developing Type 2 diabetes within 5 years.

Just over a year before in May, 2008, Tethys preceded its ADA paper presentation by announcing the commercial launch of the DRS to the press. [42] Interestingly, The San Francisco Chronicle, in an interesting twist of either conceptual maladroitness or prophetic insight, appropriately called the DRS a "risk test" in the article's title, but a "diagnostic test" within the piece itself. This given that the technological and commercial point of greatest innovative impact the DRS sought to make was as a unique predictive risk tool.

Indeed, as diagnosis occur *post-facto*, DRS technology cannot be seen as a "diagnostic tool" but as a "predictive" one. What makes the PreDx™ DRS innovative are its claims to a predictive accuracy 50% greater than the most reliable current Type 2 diabetes diagnostic test—the Oral Fasting Glucose Tolerance Test (OGTT). Nonetheless, I argue in this chapter that it in practice, it could become both: the prediction itself will convey a diagnostic interpretation of a certain biological inevitability.[45]

The rather imprecise use of the term "diagnostic test" in the San Francisco Chronicle piece suggests a possible technological determinism informing contemporary understandings of pathophysiology—as well as collapsing previous temporal frames associated with these understandings. New discourses of biological latency, process, and inevitability arise in new socialities within both old and new venues. This chapter later engages the dual discursive and spatial spaces of these new technologically mediated understandings of the subject body's relationship to both time and process.

Materially, Type 2 diabetes diagnostic tools such as the (Hemoglobin) HgA1C, the OGTT, and for that matter the glucometer, are harder unitary device technologies easily recognized as distinct objects. Their mathematical hybridity has been amalgamated and

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[40] Along these lines, it would serve well to remember that the American Diabetes Association (ADA), unlike its British counterpart, was collaboratively founded by clinical scientists and the private sector; the British Diabetic Association (now Diabetes UK), in contrast, was originally a grassroots organization founded by diabetes patients.

[42] SF Chronicle, May 27, 2008. "Emeryville Firm Devises New Diabetes Risk Test."

[45] The ambiguous definitional tension between diagnosis and risk prediction is all the more amplified by the name *PreDx*: *Dx* is medical shorthand for *diagnosis*. So does the PreDx™ DRS *predict*? Or, is it *Pre-Diagnosis*? Is *Pre-Diagnosis* the same as *early diagnosis*? If so, then early diagnosis is not prediction but diagnosis itself.

hardwired into a unitary technological device. However, the PreDx™ DRS is a calculation, an algorithm comprised of individual biological assessments (of which the OGTT is but one) inserted into a mathematical algorithm predictive of individual Type 2 diabetes risk.

Materially intangible predictive tools such as the DRS, this chapter argues, through their sheer multivalence, can become objects or things through practice, as a technology of risk, and component of future formulaic predictive tools. I use the term *predictive tool* interchangeably with the word *technology* as *things*, but also as *techniques*. By techniques, I mean the agglomeration and conglomeration of networked practices in action. These networked practices in action are informed by calculative agencies of both biopolitical and biocapital institutions, such as public health, and insurance, biomedical research, and medical device companies, respectively. I'd specifically next like to address what constitutes the DRS in terms of new networked practices of biological assessment.

The DRS assesses these *biomarkers*: age, gender, BMI (body-mass index), waist circumference[47] and family history, in addition to fasting glucose tolerance (OGTT), serum cholesterol and triglyceride levels. In this sense, the PreDx™ Diabetes Risk Score (DRS) is not an innovative technology in the form of new hardware. Rather, it is mélange of calculations based on physiological and familial assessments in a pre-identified population of high-risk individuals. Innovative technology, however, requires the creation of a new language, a language temporally oriented toward the future it purports to predict.

Speculative Grammar

Kaushik Sunder Rajan (2006) outlined the means by which capital has been reconfigured along new lines of biological valuation based upon new modes of exchange. Locating Marx's preconditions of modern capital formation successively in feudal, agricultural, and industrial societies, Rajan notes the emergence of *biocapital*, a confluence of the life sciences, capital, and technology, which, though co-constitutive, are asymmetrical in causality. Using Althusser's term *overdetermination*, Rajan sees the life sciences and technology as structurally and contextually overdetermined by the dictates of diverse capitalisms of diverse interests that seek to market, patent, and commodify life forms and technologies (Rajan 2006:6). Older forms of industrial and merchant capital combined with advances in science and technology, have evolved into and been subsumed by the newly emergent, amorphous financial ground-substance called biocapital (*Ibid*: 10).

Rajan saw in biocapital networks of competing notions of risk, interest, scale, and ownership, whose contestation and cooperation over what knowledge is public and private, is the driving force and creative tension behind the generation of biotechnological capital. It is a new form of speculative capital, or risk, which Tethys seeks to attract in order to market its DRS risk prediction technology. Commercial capital and venture capital produce different knowledge demands and products, but both reproduce the very structures of capitalisms, writ plural, as examples of different modes of capitalistic production. Rajan used Foucault to make to make an argument—that an analysis of the political economy of exchange, or for that matter, the item of exchange, carries with it an epistemic, discursive, and in the case of biocapital, institutional notions of value that are consequential of structural articulations based on idiomatic forms (or categories) of *grammar* (cf. Dumit 2003).

[47] Waist circumference does not figure into most medical risk assessments for Asian, particularly South Asian male populations. High T2D prevalence in these populations exists independently of waist circumference.

The following quotation illustrates how language and value intersect with exchange and time.

> The performance of the PreDx™ DRS model was very similar in the training and validation sets, suggesting that the model is not over-fit and may be generalized to other populations. Moreover, the performance of the PreDx™ DRS model was superior to other clinical measures in identifying a high-risk subpopulation—this model performed better in assessing T2DM risk than fasting plasma glucose, fasting insulin, HOMA-IR, HbA1c, and a model derived from noninvasive clinical measures (Urdea 2009).

In arguing for the accuracy of the PreDx™ DRS in terms of generalizability, Tethys claimed its model "…superior to other clinical measures in identifying a high-risk subpopulation…" Nowhere is race mentioned, despite the fact that the company sought to test its DRS on an *African American* population. Secondly, fasting plasma glucose, fasting insulin, HOMA-IR, Hemoglobin A1c are all *diagnostic* tests, not *risk prediction* technologies. This grammatical misappropriation of past tense diagnostic technologies by future tensed orientations of risk of which the DRS claims to fill, is an amazing temporal sleight of hand. And lastly, and perhaps most significantly, while the ability to clinically identify high-risk subpopulations is indeed important, it could be also argued that social and community analyses could produce equally if not superior assessments.

Another example of biotechnology industry grammar containing scientific claims couched in both the legal language of conditionality (risk) and the market language of possibility (or interest) reads:

> This presentation may contain forward-looking statements which are based on current assumptions and forecasts made by Bayer Group management. Various known and unknown risks, uncertainties and other factors could lead to material differences between the actual future results, financial situation, development or performance of the company and the estimates given here. These factors include those discussed in our public reports which are available on our website. The company assumes no liability whatsoever to update these forward-looking statements or to conform them to future events or developments. (*Science for a Better Life*. Bayer Health Care Presentation. JP Morgan Health Care Conference, January 12, 2010)

However, this particular grammar is not a monopoly of the North, and Rajan shows how actors in India, in concert with the state, have formed new grammars based on new networks of interest and contestation of global risk, knowledge, and markets that challenge, augment, and reshape both global markets and global knowledge production.

The PreDx™ Diabetes Risk Score purports to predict the onset of Type 2 diabetes within five years in individuals with normal blood glucose levels. While I give attention to this particular Type 2 diabetes risk assessment tool, a multitude of other risk assessment formulae have emerged in its wake. Therefore my enquiry does not merely interrogate PreDx™

technology, but the temporal and discursive shift this technology, I will argue, effects: a *grammatical* and interpretive shift from diagnosis to prediction *as diagnosis*.

An instructive answer to this question comes directly from the DRS literature. In a subsequent paper, the Tethys authors calculate a consumer savings in Type 2 diabetes costs of at least $3500 per patient from its early detection PreDx™ technology.[48] Based on this projected cost savings amount, the authors suggest a $3500 fee per PreDx™ test. The incremental cost effectiveness of the technology is projected as inclusive of the calculated risk that the asymptomatic individual with a high DRS score will indeed progress to Type 2 diabetes status within five years of taking the test. The authors went on to conclude that projected over a ten to fifteen year period, the PreDx™ could possibly result in a quality of life savings of nearly $50,000. The projected savings were based on the identification of high-risk individuals through the PreDx™ risk score and the subsequent implementation of appropriate intervention strategies.

However, an article published a year before announcing the development of the DRS; Tethys BioSciences floated a cost savings of $10,000 per patient.[49] This opportunity cost was based on the assumption that those individuals made risk aware by their DRS result will take proactive lifestyle (diet and exercise) measures in avoiding later biomedical and pharmaceutical interventions. So what to make of this?

The cost savings claim of $3500 covers the five year window from identification through a high PreDx™ score to the manifestation of Type 2 diabetes - in effect, the period from asymptomatic identification to clinical confirmation of Type 2 diabetes; The $10,000 savings claim, judging by Tethys' language, refers to the period of identification of high-risk up to the prediabetic/diabetic stage. Lifestyle interventions (diet and exercise) were employed by this subgroup before and instead of pharmaceutical implementation.

In extension, the $50,000 future cost savings projection applied to a select subset of high-risk individuals who were identified early through the PreDx™ and whose therapeutic futures were envisioned in terms of both lifestyle and pharmaceutical regimentation. It must be kept in mind that the cost savings amount was the projected upper limit claim. However, I suggest that these three costs savings projections and their temporal and physiological representations produce new discourses out of old cloth.

First, it is already known that eighty percent of prediabetics can normalize their blood sugar levels through diet and lifestyle interventions alone (Neufer and Booth 2005).[50] Second, Type 2 diabetes patients who meet the American Heart Association's weekly aerobic exercise targets and dietary recommendations can sharply reduce if not eliminate their dependence on medication (Suitor and Kraak 2007). Lastly, the Physicians Committee for Responsible Medicine argues that Type 2 diabetes pharmaceutical interventions can be eliminated through adherence to a high fiber, complex carbohydrate based vegan diet (PCRM 2006 Annual Report).

So while Tethys' technology may have the ability to collapse time frames and predict pathological destinies, the ethos of pathos remains embedded in the social body. If not solutions, then possibilities of caring for the self do indeed exist; yet, which as lived practices remain quite uncommon.

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[48] (Sullivan, Pollock, Garrison, et al "Long Term Cost-Effectiveness of a Diabetes Risk Score." ADA Paper, 2009)
[49] SF Gate, May 27, 2008. "Emeryville Firm Develops Diabetes Risk Test."
[50] Pharmaceutical interventions have increased in research priority to the point where the only study which examined exercise alone in delaying T2D onset has been conducted in China. *See*, ScienceWatch.com, *Interview with David Nathan*, July 2009. Cf. Kitabchi, et al. 2005.

My larger project necessarily places ethnographic and discursive analytic attention onto how these tools and techniques introduce and operationalize new pharmaceutical entrées within emerging articulations of Type 2 diabetes treatment rationales and imperatives. In the case of DRS technology, we've been given a truth claim by its authorial representatives concerning a new predictive form of technological truth-telling. Without prejudging the content of this truth claim, I mapped how this discourse travels and is taken up by newly enrolled actors, institutions and stakeholders.

Secondly, in following the circulation of discourses about the DRS and prediabetes, I questioned whether, and if so how the shift from diagnosis to prediction motivates actors to act within these new moral economies of personalized cardiometabolic risk. Will these individuals begin exercising regularly and changing their eating habits? In what ways will the cultural continue to privilege the pharmaceutical?

The CEO of Tethys BioSciences envisions a future personalized medicine, not in terms of disease prevalence, but disease risk. The DRS privileges an approach he calls "predictive personalized medicine."[51] As a new form of predictive personalized medicine, the DRS's function l to individuate risk serves as an incentive to normalize, naturalize, and ultimately, reify, its use. If this is accomplished, it can hope to enter into the moral economy of a new Type 2 diabetic literacy and practice — a logical, but potentially flawed processional rationale. I will go into further detail concerning this flawed rationale later in this chapter. But first, I would like to explore the global context within which Type 2 diabetes currently exists, and the implications of this emergent technology and the economic stakes involved.

Venturing Capital on The Market Body

Unlike glucometer technology or pharmaceuticals, whose market plans envision growing consumer bases of repeat buyers, a diabetic risk score assessment is a one-time use technology. Therefore from a global perspective, I question whether idealized forms of medical inclusion such as insurance coverage in the US, whether private or public, even if achievable, could garner the market share promised by the changing demographic, economic, and epidemiological factors driving the Type 2 diabetes epidemic/pandemic. China's economic rise and subsequent increases in its urban population, combined with its previous one child policy, have facilitated a doubling of its Type 2 diabetic population in the last 12 years to nearly 57 million individuals — a number nearly equal that of the entire population of the United Kingdom, and more than double that of the entire US Type 2 diabetic population. Added to this phenomenon, the Chinese health care system has been quickly moving to a single payer system. The emergence of this large and exponentially expanding population of Type 2 diabetes patients/consumers— in an economically more prosperous society with sufficient resources to pay for out of pocket medical expenses— portends a boom in the Type 2 diabetes market (Ward 2008).

Given the growing size in the number of confirmed Type 2 diabetes cases in China, one can extrapolate upon the number of *hidden* or undiagnosed diabetics and prediabetics in the country. Of particular significance to our discussion is the number of individuals in China who currently are at risk of developing Type 2 diabetes. It then becomes quite possible to imagine the potential of the PreDx™ DRS market in China alone.

Further, India, the nation with the largest number of Type 2 diabetics in the world, is experiencing smaller, albeit geometrically significant rises in Type 2 diabetics as it, too, becomes

[51] *SF Gate*, May 27, 2008

more economically prosperous (Hoskote and Joshi 2007). We must therefore ask whether medical inclusion in the form of insurance coverage in the US of predictive and diagnostic instruments such as the PreDx™ DRS, are economically relevant, necessary, or even anticipated marketing drivers of Type 2 diabetes technological research and deployment. Perhaps even more significantly, class crosscuts both China and India's Type 2 diabetes populations in ways inverse to the US experience: While obesity and Type 2 diabetes in the US disproportionally affect lower socioeconomic groups and has penetrated deep into rural areas, in China and India, the growing Type 2 diabetes illness prevalence corresponds to both countries' rising urbanized middle and upper classes (Ward 2008; Hoskote and Joshi 2008). These demographic and socioeconomic factors make both nations attractive long term prospects for future diabetes industry efforts at market penetration.

However, although market logic on this side of the Atlantic and Pacific sees China and India as future sites of US biotechnological penetration, several problems trouble any robust short term success. The biotechnology portion of my fieldwork brought to light the economic and regulatory climate that companies such as Tethys BioSciences found itself operating within. Precipitated by the banking crisis of 2008-2009, a dovetailing US economy brought new urgency to biotechnological profitability. Private venture capital firms became less willing to fund projects, while demanding that funded companies convincingly show profitability in a shorter period of time.

At a gathering of venture capital executives, clinical and biotechnology researchers in South San Francisco, I came to better understand the contemporary urgency of biotechnological profitability within the economic and regulatory zeitgeist of biocapital (Rajan). Conducted by a private biotechnology and venture capital consortium in the San Francisco Bay area, the meeting's organizers brought together those seeking funding with the funding themselves. Before the meeting, research scientists with ideas seeking start-up or next stage funding circumambulated the room, making pitches and proposals of marriage to the arrayed set of venture capitalists.

My concern focused on the economic and regulatory climate for US biotechnology firms seeking to enter Chinese and Indian Type 2 diabetes markets. I struck up a conversation with a Silicon Valley venture capital partner about the situation. Ronald made it clear that many hurdles face US biotechnology and pharmaceutical firms desiring entry into the Chinese, Indian, and even European health care markets.

> The United States remains the best return on investment dollar (ROI) health care investor nation in the world. There are too many rules and regulations in the various European countries — European penetration requires strong distribution links that are difficult to forge. Yes, China and India's Type 2 diabetes populations and increasing wealth, appear, on surface, lucrative sites for future investment. However, they should both be viewed within long rather than short term investment strategies: China is a regulatory nightmare; in India medical devices find distribution mainly through physician networks. Therefore, both present distinct but powerful distribution problems. One needs a global partner to penetrate either market.

Ronald added that "Despite its growing economy, India has not yet developed a consumer base sufficient to meet the demands and expectations of international capital investors in biomedical technology and pharmaceutical firms." As described above, the challenges facing western market penetration into the Subcontinent preclude any short term financial reward. However, it remains a vast repository of biovalue for Type 2 diabetes researchers.
According to Ronald:

> India has the largest number of cases of diabetic nephropathy (kidney disease) among Type 2 diabetics in the world. This makes it a great place to conduct offshore clinical trials. There are CROs (private clinical research organizations) everywhere and the FDA accepts research conducted by these CROs among Indian populations.

However, sovereign power as a lens onto the workings of biotechnological capital exposes the ambiguities and uncertainties produced through institutional and market relations. Biomedical technology and venture capital firms argue that the FDA also creates ambiguity and uncertainty. Another venture capital partner chimed:

> The agency (FDA) is in a confused state. They are overly concerned about the 'side effects' of pharmaceutical drugs. But everything has a side effect. The problem as I see it is that we have different notions of risk. On our side, market risk has well defined limits; however, the FDA has no internal rules or consistency. I get more information from CEOs and other private networks than from the FDA. Right now, *the FDA is the biggest risk* to product development. (*Author's* emphasis)

He was uncertain as to whether the FDA's aversion to risk was due to the Avandia[52] case, or government reorganization originating from within the new Obama administration. "The case of Vioxx[53] further complicated the issue."
He continued:

> The FDA forgets that medicine is about risks and benefits. This can be easily reconfigured by ending direct to consumer advertising. They should also get rid of lawyer to patient

[52] Avandia, a widely prescribed drug touted as a breakthrough treatment for diabetes, was pulled from the market after it was shown that it led to an increased risk of mortality due to heart attack. *See* Greene, Jeremy. 2007b. Pharmaceuticals and the Economy of Medical Knowledge. *Chronicle of Higher Education*, November 30.
[53] Vioxx was pulled from the market after it was discovered that the anti-inflammatory drug also increased the risk of mortality due to heart attack. There is evidence that the manufacturer, Merck, knew about these dangers yet sought to maximize the drugs profitability before publicly acknowledging the risks the drug presented. *See*: "Dangerous Data: Despite Warnings, Drug Giant Took Long Path to Vioxx Recall." *New York Times* November 14, 2004.

> advertising. The FDA should move from health protection to health promotion.

Right on cue, one of his colleagues quickly chimed in, "The FDA needs to recognize that medicine is not only about risks and benefits, but about rewards also." However, in the case of diabetes technology and pharmaceutical development, a general partner in a Silicon Valley venture capital company explained,

> 2009 was the worst year for biotechnology companies during this recession. These biotech companies currently worry over, not only the commitment, but the viability of funding syndicates and networks into the near future.

Moreover, 2009, he continued, exists within a longer history.

> Health care technology financing dried up during the internet and dot com bubble during the mid-to late 1990s. After the bubble burst in 1999, financing became scarce for both health care and internet technology markets. ..But, 2009 was much worse.

He linked the events of the late 1990s and 2009 to the dyspepsia affecting venture capitalists' current appetite for risk. "If, today, you tell a venture capital firm that your product will need a seven year period from development to market entry—your presentation is over."
The current economic situation facing biotechnology companies such as Tethys demands sufficient scriptural grammar to successfully negotiate the rough currents of the contemporary venture capital market. This means generating convincing data in a shorter time that has greater market coherence and adhesiveness.

I situate this conversation within these productive, profitable, and often disruptive spaces of this Type 2 diabetes technological moment where diagnostic technologies are gradually being supplanted by new predictive risk engines such as the PreDx™ Diabetes Risk Score. Further, these emergent spaces create more market and clinical possibilities for increased monitoring and surveillance of these new forms of *diagnosed risk*: glucometer and HgA1C rationales and regimes could be implemented sooner and last much longer than earlier diagnostic markets could deliver. Similarly this temporal collapse organizes new forms of pharmaceutical bioregulation against diagnosed risk, such as with the case of prediabetes.

Having placed for discussion public and private notions of risk, as well as the historical interplay between public health institutions and capital markets in producing new biological citizens, consumers, patients, and experts, I next focus attention on the difficulties involved in actually making this happen.

Bridging the Valley of Translational Death

Declan Butler's 2008 article "Translational Research: Crossing the Valley of Death," describing the gap, or valley, between translational research and improved health outcomes, elicited an outpouring of responses from clinical scientists, venture capitalists, and biotechnology and pharmaceutical stakeholders.[54]

[54] See *Nature* 453, 840-842 (2008)

Butler argued that,

> Over the past 30 or so years[55], the ecosystems of basic and clinical research have diverged. The pharmaceutical industry, which for many years was expected to carry discoveries across the divide, is now hard pushed to do so. The abyss left behind is sometimes labeled the 'valley of death'—and neither basic researchers, busy with discoveries, nor physicians, busy with patients, are keen to venture there.

Clinical and biotechnological translation has been defined in various ways: *from bench to bedside, ideas to health outcomes*, *ideas to income*, *science into market value*, and *between academy and industry*. During my earlier 2004 Silicon Valley medical technology research with The Institute for the Future as well as networking with physicists and engineers in the area from 1995-2004, I became acutely aware of these definitions of scientific translation as the term gained in currency. I had met faculty who not only collaborated with the private sector but also founded start-up technology companies and served on the boards of directors of others. Networks of faculty scientist entrepreneurs extended beyond national borders, from China to Scotland to Bangalore to Palo Alto.

However, the overwhelming majority of these scientist entrepreneurs were faculty at private universities such as Stanford, MIT, and Heriot-Watt University in Scotland. The relative absence of public university faculty intrigued me well into the period of this research project. As my previous experience had been with Stanford and Heriot-Watt faculty entrepreneurs and private industry researchers, concerns about the "corporatization" of the academy, while perhaps relevant, did not surface within these research communities, or at the time in the mind of this nascent researcher. As members of the Institute of Electrical and Electronics Engineers (IEEE) and the International Society for Optics and Photonics (SPIE), the relationships these applied scientists fostered between the academy and industry were almost seamless. This was a very different but not dissimilar planet to the technological worlds of pharma and biotech, that of optical engineers and applied physicists. I nonetheless breathed the same Silicon Valley air as did pharma, biotech, and the applied physicists—and I, too, declared it good. Now the public research sector has decided to enjoin more extensive relationships with biotechnology, pharmaceutical, and venture capital interests in bringing science to the market in delivering better health outcomes in patients.

In 2010, at the South San Francisco biotechnology and venture capital conference mentioned in the previous section, I met an official from the University of California, San Francisco's Office of Technology Transfer. When I mentioned my previous experiences in Silicon Valley, Dr. Abrego admitted that "Public universities have been slow to participate in private industry collaborations. UCSF recognizes this and is committed to becoming a major player. That is why I'm here." To this end, in 2006 UCSF opened the Center for BioEntrepreneurship (CBE) on its new Mission Bay Campus. The Center's charge to "educate and enable scientist interaction with the venture capitalist sector" consisted in part of classes taught by industry experts. Translation in this pedagogical context means guiding scientists

[55] The passing of the Bayh-Dole Act in 1980 permitted universities and non-profit organizations to obtain intellectual property (IP) rights from all federally funded research. This is the thirty year period framing this conversation.

through the process of transforming an idea into an initial public offering (IPO) on the market. The Center provided a space where academic researchers could present innovative ideas; help facilitate working teams of research and venture capital stakeholders in developing these ideas, writing a business plan, and pitching the completed business plan to potential investors.

I was invited by UCSF to attend Camp Entrepreneur, an attempt to introduce the university research community to its Center of BioEntrepreneurship as well as its efforts at fostering ties between the public university and the private sector. In light of my previous Silicon Valley experiences and meeting Dr. Abrego, I wanted to see how these efforts were taking shape. Further, I was interested in better understanding venture capital and biotech perspectives about what exactly constitutes potential value and how academic researchers come to inhabit the language of the market. Specifically, I wanted to get a clearer picture of the current market and research environment that Tethys BioSciences operates within as it attempts to translate its clinical science into income and market share.

Camp Entrepreneur was held in Genentech Hall on UCSF's Mission Bay Campus.[59] An arguably appropriate venue, as Genentech was co-founded by UCSF research scientist Herbert Boyer in the late 1970s. While Boyer was based in a public university, the fact that Genentech began with private venture capital funding illustrates, in selective retrospection, the possibilities of venture capital (or shall I say *biocapital*) in contrast with the constraints of conservative industrial bank capital. The die had been cast.

The camp was sponsored by a large multinational bank interested in fostering deeper relationships between the academy and industry. The meeting was opened by Maninder Kahlon, a neuroscientist with experience founding start-up tech companies in Silicon Valley, and who now serves as the Chief Information Officer of the Clinical and Translational Science Institute (CTSI) in the UCSF School of Medicine. "Let me see a show of hands. How many of you are MDs?" A smattering of hands went up. "OK, I'll say twenty-five percent. How many of you are PhDs—wow, sixty percent. Now, how many of you are in the venture capital or industry sector? I'll say fifteen percent?"

Kahlon opened the floor to introductions by audience members asking what brought them to Camp Entrepreneur, what questions they had coming in, and what they hoped to take out of the experience.

A venture capitalist introduced himself as having contributed to several start-up companies, with the overall experience having left him "frustrated."

> For me it's a question of translating science into market value—
> How to move translational science from the Office of Technology
> Transfer to the private sector? And what are the secrets and keys to
> making the shift from academic science to the market possible?

Another venture capital stakeholder followed, impatient with the entire translational pipeline from basic research to product development.

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[59] In many respects Genentech institutionalized the relationship between biotechnology and venture capital. See Sahlman, William A. 1990. The Structure and Governance of Venture Capital Organizations. *Journal of Financial Economics* 27(2): 473-521. *Also*, Powell et al. 2002. Spatial Clustering of Science and Capital. In 2002, the authors situated biotechnology's lifeblood in the dual streams of basic science and venture capital, of which Genentech epitomizes and from which it emerged.

> The academic sphere is too slow in getting its research out and biotech and pharma are incredibly wasteful with R and D (research and development) money. When it comes to innovation and market value, from what I've seen, corporate strategies see creating repeat users as more lucrative and important than creating new product.

Maninder Kahlon agreed that new therapeutic interventions have not kept pace with the amount of scientific research and funding channeled toward these innovative projects.

> The NIH (National Institutes of Health) responded by establishing the Center for Translational Science Awards (CTSA).[60] In 2006, UCSF received a five year, $117 million award for the creation of the Center for Translational Science Institute (CTSI) here at UCSF. UCSF and Harvard are the largest recipients of this funding. Our mission is to accelerate research to bring health to more people more quickly.

In moving toward this goal, the CTSI aimed to facilitate matchmaking amongst science and industry as well as with successful scientists and CTSI staff, many if not most of whom, like Kahlon, have significant amounts of experience in the high-tech and venture capital sectors. She contrasted the "Old World" with the "New World" model the Center for Translational Science Institute represents.

> The Old World model scientists used to entertain private sector interest in their work usually through individual efforts—internet searches and seeking and securing valuable mentorship which could provide an entrée into private sector venture capital networks. The New World model that the CTSI hopes to create centers on creating a one-stop site containing all potential sites of intramural funding and venture capital collaboration. We help researchers demonstrate measurable research changes in community health at the end of the translation chain.

As part of introducing academic researchers to the ethos and practice of the market, UCSF, through the Center for Translational Science Institute, now charges researchers a fee for these services after the first hour of consultation.

> We don't want to turn good scientists into bad entrepreneurs. We can't force them to become entrepreneurs but we know that there

[60] The amount of funding the NIH provides for translational research amounts to around one percent of its total research budget. The majority of funding is still allocated to basic research. The larger point is that both public and private sector research have not produced the medical breakthroughs justified by the amounts of funding spent over the last twenty years. For example, the FDA reports that in 2008, almost 800,000 biomedical research papers were published, but only two new drugs were approved by the agency. See: http://opinionator.blogs.nytimes.com/2011/05/02/helping-new-drugs-out-of-academias-valley-of-death. *Accessed* : 5/19/2011.

> are good scientists out there who would make great entrepreneurs. We just have to find them and provide resources necessary to facilitate their work and nurture their entrepreneurial spirit.

I wondered how exactly a nurtured entrepreneurial spirit could not help but animate the good scientist's conceptualization of and approach to robust research. However, this comment describes the zeitgeist of scientific practice, where science and entrepreneurship exist dialectally in the production of new knowledges, technologies, and forms of health. The waste of both private and public research funding in the past and poor health outcomes creating the present valley of death now demands labor from the science of the biopolitical nation-state, or the public research sector. I argue that the ascendant but conditional biocapital formation outlined by Sunder Rajan today inversely desires to *make biopolitics work for it*. Crudely put, public sector science must no longer "see (only) like a state,"[61] it must "see like the market," and reorient research accordingly.

The Valley of Death also represents a very real social space between the scientific community and patients, where the prematurely dead are buried in the absence of biotechnological deliverables. From within the valley floor, start-up companies sprouted by seed money planted deeply within the newly transported and terraced soil of basic science, will bloom fragrant flowers which will eventually bear the fruits of health, wealth, and knowledge. Where once there was death, there is life. Prognosis as predicate to speculation, because where there is hope there should be profit. Profit is health. Health is wealth. But nowhere in this narrative can we find a definition of translation as *communicating science to the public within a bioethical framework* firmly anchored within the morass of the valley floor itself.

The inherent ambiguities within Franklin Knight's economic theory and practice of anticipating profit through calculated risk embraces the economic rationale of the biomedical market, of which the DRS, for example, is a part. However, it also embraces, if not requires, the predictive and diagnostic ambiguities inherent to these technologies and interpretive frameworks, as discussed in the previous chapter. Assuming present risk based on recent basic research makes these innovative biotech and biopharma futures possible. Risk and research are finding greater logical synchronicity in both public and private laboratories and clinics. In the case of diabetes, evaluating risk takes on different research imperatives and forms of inclusion within public biopolitical and private biocapital (or biomarket) spheres.

Inclusion

I have since learned that in fact, there are many diabetes risk scores, not only in the US but around the world. Some are biopolitical risk scores of nation-states (Australian, Chinese, Indian, German, Finnish, UK, Danish, etc.) or biomarket risk scores such as Tethys' PreDx™ Diabetes Risk Score. Several of the national diabetes risk score evaluations are available at no cost online. Biomedical institutions have been developing their own diabetes risk prediction models, some

[61] In Seeing Like a State (1998), David C. Scott argued that state engineering of the social is predicated upon the 1)administrative ordering of nature, 2) mastering of nature (both biological and human) through epistemic confidence in the telos of scientific and technological progress will address and satisfy human needs, 3) a state ready and able to deploy power authoritatively and without reservation in actualizing the preceding objectives. 4) The last necessary element for successful state run social engineering is a submissive civil society unable to resist such plans (Scott 1998: 4-5).

amalgams of the DRS and older diagnostic technologies such as the Oral Glucose Tolerance Test or the Hemoglobin A1C Test.[62] Much to my surprise, I noticed that different ethnic groups were assigned different levels of risk in different national diabetes risk scores. Further, ethnic groups considered high-risk in one country, were not even represented in terms of risk in another. For example, on the UK Diabetes risk score website, the individuals shown and made narratively available at the click of a mouse were overwhelmingly South Asian. No Afro-Caribbeans or Africans were visually featured or textually mentioned.[63] While arguably the literal state of epigenetic affairs in the UK differs from the US in terms of demographics, I make this point to highlight ways in which the biopolitics of race and diabetes risk vary in different national contexts.

The main difference between the biopolitical diabetes risk score of the nation-state and the biomarket risk score of the private sector, obviously, rests in the envisioned reach of the score. National risk scores are mostly nationally bound, whereas the private sector generated diabetes risk score ideally seeks universal acceptance and applicability. Further, although national and institutional diabetes risk scores have ready applicability in their respective clinical spheres, the Tethys DRS seeks to occupy not only these older biopolitical clinical spaces but also the global space of the international diabetes market. This it sought to accomplish, I argue, by building race into the Diabetes Risk Score technology without having to articulate the messy business of *race as risk.* I next turn my attention to Tethys' attempt at generating biocapital value from older biopolitical discourses and categories of race.

A Prelude to a Sunday Walk

As a laboratory test, the DRS carries an added health care cost: it is not yet covered by insurance plans nor is it, by economic extension, available to those high-risk groups in the US most prone to Type 2 diabetes—Latino American, African American, and some Native American populations. In addition to environmental, social, and economic factors, these groups are less likely to have health insurance and most likely to present to hospital with chronic hyperglycemia and undiagnosed diabetes. Then there is the relationship between the diagnosis of Type 2 diabetes, the emergence of the DRS, and the challenges these technologies present in creating inclusive health care coverage.

To illustrate this further, a diabetes education coordinator in Oakland I interviewed was quite aware of the emergence of DRS technology and the possible ramifications of its implementation. Betty Washington, a Type 2 diabetes patient herself, made it clear that most insurance companies reject patients with a diagnosis of Type 2 diabetes. If it weren't for the medical coverage provided by her employer, she herself would be uninsurable. "A diabetes diagnosis marks people," she said.

I contacted Betty Washington in the spring of 2009 about my possibly conducting participant observation as well as interviews at the diabetes prevention program she runs at the Alameda County Department of Public Health. After telling her about my project, she enthusiastically and wholehearted gave me support in terms of interviews, introducing me to her staff of certified diabetes educators, one of whom, Darlene, I shadowed in the field. The diabetes

[62] The University of Arizona and Arizona State University's BIO5 Institute is developing an alternative diabetes risk prediction model. See http://tucsoncitizen.com/morgue/2007/10/25/66840-ua-research-to-predict-who-may-get-diabetes/. *Accessed* 6/18/11.

[63] http://www.diabetes.org.uk/Riskscore/. *Accessed* 7/29/2011.

program is housed within a maze of offices in what was once a former shopping center in West Oakland. Located in a high crime, high unemployment and underserved area of the county, various county agencies house themselves there as a sort of one-stop shop for social welfare and other services. Betty's diabetes educators teach diabetes classes in English, Spanish, Chinese, Hindi/Urdu, and Vietnamese, among other languages.

According to Betty, Tethys BioSciences, creator of the PreDx™ DRS, offered to implement DRS testing locally among two groups: 1) children, and; 2) adult prediabetics. In the case of children, it was proposed that testing occur in schools to determine the number of at risk individuals present in the youth population. However, testing children presented several challenges.

For one, testing children, even in terms of predictive risk, ran the very real possibility of ascribing a label which would eventually disqualify them from insurance coverage. In confidently predicting Type 2 diabetes onset in the asymptomatic individual, a large span of therapeutically effective time, particularly in the case of children, could be lost due to the loss of or inability to secure health insurance. As I argued earlier in this chapter, the DRS represents in practice the synonymous interpretation of predictive risk as diagnosis itself. The second and equally significant hurdle revolved around the ethical issues concerning obtaining consent in testing children. This brought into tension the opportunity to both test the DRS instrument and also gain a clearer understanding of the numbers of latent diabetics existing within specific high-risk youth age groupings.

In light of the above factors, Betty related that Tethys decided against pushing for DRS testing among school age children in favor of testing adult prediabetics. However,

> Tethys really wants to test its DRS on a large group of African Americans. They want to test their instrument on a high-risk Type 2 diabetes population and produce data that will confirm the effectiveness of the risk score. Presenting evidence based on a relatively homogeneous Danish population is not convincing enough.

The proponents of the DRS cite its cost saving over the lifetime of a Type 2 diabetes patient due to the test's early warning capability (more on this later in this section). Betty saw this cost saving claim as both the assumption and market justification driving Tethys' effort to test prediabetics. The five year risk prediction to Type 2 diabetes onset model, she explained, is offered as an incentive toward more committed changes in diet, lifestyle, and pharmaceutical practices in the newly aware subject. Hence, its market justification. But to make the DRS truly marketable by increasing venture capital infusions and clinical acceptance, Tethys could surely use those *African American* research participants. How to best attract them?[64]

Steven Epstein's (2007) argument that "inclusion" within racial categories used in medical research fragments the lived realities of social class and health disparities, took on a

[64] The originators of the Finnish Diabetes Risk Score, the DETECT-2, in citing the homogeneity of its research population as a methodological weakness, expanded its study to Mauritius in order to obtain the heterogeneous population sample it desired. See: Marjan Alssema, et al. 2009. "*The DETECT-2 Update of the Finnish Diabetes Risk Score for Prediction of Type 2 Diabetes*." The 69th Scientific Session of the American Diabetes Association, New Orleans, LA. http://professional.diabetes.org/Presentations_Details.aspx?session=3428. *Accessed* 30 November 2010.

different inflection in the above case. Fragmenting a population within a category without truly understanding the social realities of said group and how these social realities reproduce the category, is methodologically flawed. I must argue here that while Tethys' technology may have the ability to collapse time frames and predict pathological destinies, the ethos of pathos remains embedded in the social body not the racial body it seeks to use for calibrating its Diabetes Risk Score instrument.

While I challenge the assumption the DRS will motivate actors through the new moral economy of risk it seeks to generate, I wish to next focus on the work that these forms of inscribed facts and truths perform in erecting the edifice of assumption itself. The development and deployment of the DRS offers a glimpse into the ways in which risk capital paradoxically produces new ambiguities in generating new facts, interests, and investments.

The predictive claim the DRS makes offers new discursive and ethnographic possibilities concerning technological representations of the body—as open to discovery and narrative depiction—as well as a scripturally foreclosable, patentable, intellectual property. However, while technological and scientific knowledge can be owned, its interpretation remains contested terrain. It is here where ambiguity and ambivalence can overlap, blurring predictive, diagnostic, prognostic, and therapeutic anticipations and forms of evidence within contested notions of the "normal" and the "pathological" (Canguilhem 1966 [1991]; Whitmarsh 2007).

In Science as Vocation (1919), Max Weber found less critical concern about the conceptual and methodological validity of scientific work, than about how it presupposes "what is worth being known." He argued that this presupposition of knowledge value cannot be proven empirically, which problematizes understandings of what exactly constitutes meaningful scientific work. Weber concluded that, in the problematic analytical search for meaning, room exists only for *interpretation*. Agency rests in our acceptance or rejection of these interpretations of scientific knowledge value, depending on our positionality in the world (Weber 1919: 143).

Weber instructively informs this discussion of how scientific knowledge production, in this case the DRS, but more broadly and inclusively, T2DM diagnostic technologies as well, create room for interpretive ambiguity—and how separating the facts from subjective interpretations and discourses of value—problematizes what is truly worth knowing about T2DM and the body. Subjective positionalities—patient, investor, educator, clinician—differentially envision and (re)produce both value and knowledge. What is still left outstanding here are the ways in which the subject comes to determine value, knowledge, and the factual in creating both meaning and a meaningful life; and whether science has a role to play in this process of emergence. What is also left outstanding is the question of power and its ability to construct value, prioritize knowledge, as well as author and articulate both the language and the narrative of facticity.

I submit that the DRS effects a collapsing of the temporal frames formerly associated with risk, prediction, and diagnosis as bounded categories. This temporal collapsing of evaluative Type 2 diabetes categorical gazes upon the body (such as race, ethnicity, phenotype, genotype, etc.) combined with the visual rationalities offered by DRS, HgA1C, or blood glucometer technologies—offer new interpretive schemata for Type 2 diabetes fact-making. As such, diabetes measurement technologies, whether diagnostic or predictive, arguably function as interpretive device technologies within changing temporal and disease classificatory schemes and clinical understandings.

Therefore, Type 2 diabetes, as well as the market, does not recognize national boundaries, epistemological disjunctures, or other social and cultural constraints. A cursory

examination reveals the scriptural and economic pragmatics of the contemporary Type 2 diabetes moment in ways that further contextualize US Type 2 diabetes narratives of inclusion and exclusion, and the role the DRS seeks to play.

Citational Momentum: Attracting Investment, Generating Interpretive Ambiguity

In Tethys' ADA paper[65] it is difficult to accurately determine either the complete list of biomarkers, laboratory tests, or exact mathematical formulae used to calculate the Diabetes Risk Score. What the article does emphasize are the technologies and statistical models used in making these bio-assessments—but no detailed accounting is given of exactly what laboratory and clinical categories and methods were involved in creating the DRS. Also, the lead authors of the article are themselves employed by Tethys BioSciences; the secondary authors are research scientists from Denmark whose earlier research provided the population sample used in the Tethys DRS project.

The marketable certainty of an expanding Type 2 diabetes consumer/patient base is attractive to investors. However, cumulatively published documentation of data, analyses, and results are first required to create the accumulated citational momentum necessary to establish, as we have seen, productive *interpretive* ambiguity through Rajan's notion of *grammar* to fuel interest and enroll actors. The Tethys ADA paper is a case in point.
While the paper is entitled "Validation of the Diabetes Risk Score,"[66] an accompanying disclaimer, similar to the forward looking document described earlier about Bayer, reads

> Data presented in this publication are based on the Tethys research platform. This paper does not represent the performance characteristics of the Tethys PreDx™ Diabetes Risk Score. For information on performance characteristics for Tethys products, please contact your Tethys representative.

This is precisely what Derek de Solla Price et al. (1965) called the circulation of "Networks of Scientific Papers" in the creation of "Invisible Colleges" (Price 1963).[67] Price located this intellectual activity within the social realm of knowledge production rather than being a true descriptor of the phenomena under scientific scrutiny. Corporate and state influences affect scientific scriptural production by shifting innovation incentives away from academic prestige toward patent commercialism. But as we have seen, the valley of translational research death articulated in the present arguably presents one example of the scriptural shift away from the academy to the market that Price saw emerging in the 1960s. Today, market hegemony over the

[65] McKenna, Lyssenko, Rowe, et al. *Validation of the Diabetes Risk Score, a Multi-Marker Panel that Assesses the Risk of Type 2 Diabetes: Combined Results of the Inter99 and Botnia Studies*. Adapted from poster presented at the 69th Scientific Sessions of the American Diabetes Association (ADA), June 5–9, 2009, New Orleans, Louisiana.
[66] McKenna, Lyssenko, Rowe, et al. *Validation of the Diabetes Risk Score, a Multi-Marker Panel that Assesses the Risk of Type 2 Diabetes: Combined Results of the Inter99 and Botnia Studies*. Adapted from poster presented at the 69th Scientific Sessions of the American Diabetes Association (ADA), June 5–9, 2009, New Orleans, Louisiana.
[67] In *Little Science, Big Science* (1963), Price argued that the creation of "Invisible Colleges" of accumulative fact-making through scientific publishing was necessary to generate the citational momentum required to attract allies, investment, and other forms of scientific capital. Tethys, like many other biotechnology firms, is engaged in precisely this effort of scripturally transforming novel science into big science and big business.

academic and public spheres of research can perhaps be better described in terms of market dependence, or more charitably, market reliance, upon academic and public sector research.

Over the course of this project I noticed that many academic and professional digital publishing companies, a fair number of which provide the .pdf files of many articles we use today in conducting scholarly research also perform another role in disseminating and circulating information. They also organize conferences and symposia that bring together clinical, venture capital, and biotechnology firms. These meetings serve the purpose of fast tracking the process of research, innovation and publication in the pursuit of market tractability and investor interest. With meeting fees of between $995-$1995, expensive journal subscriptions stretching even well-endowed university library budgets, and online scientific articles hidden behind paywalls, informational gatekeeping by web publishing interests redraws the lines of both access and value.[68]

Publishing has in many ways been relegated to an auxiliary but strategic role in biotechnology as a tool to ward off future potential claimants of discovery and intellectual property. Venture capital floods in and begins to expect innovation: scientists are attracted to industry, cashing in on the symbolic capital of the burdensome academy for the material capital offered by comparatively more efficiently-run corporate entities.[69]

However, in the process, new standards of excellence are established. For example, scientific innovation is now judged not only by its individual merit or usefulness to humanity, but also by its ability to attract venture capital ("vulture" capital as it's euphemistically known in Silicon Valley—"money consuming ideas" as one biotechnology engineer put it), launch successful IPOs, and to subsequently sustain rising stock prices. *Eureka* is no longer merely synonymous with *discovery*, but with the *sale* of a small, innovative, firm to a larger one. What is being purchased are not simply assets, but practices informed by new ways of socializing experimentation which older companies' more ossified structures and paradigms, did not, or could not, foster. And this includes older commercial banks vis á vis venture capital firms. "Legacy investments come with legacy mindsets."[70]

In this light, the sponsored predictive claim the DRS makes offers new discursive and ethnographic possibilities concerning technological representations of the body—as open to discovery and narrative depiction—as well as a scripturally foreclosable, patentable, intellectual property. For example, Tethys required that all PreDx™ DRS testing of blood samples occur at its home laboratory site. An estimate of the patient's five-year T2D risk prediction projection would then be furnished to the physician (Urdea et al. 2009: 753). While technological and scientific knowledge can be owned, its *interpretation* remains contested terrain with in the valley of death. It is here where ambiguity and ambivalence can overlap, blurring predictive, diagnostic, prognostic, and therapeutic anticipations and forms of evidence.

However, there has been some pushback in some clinical circles about the PreDx™ Diabetes Risk Score, its biostatistical methodologies, and claims of superior predictive power.

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[68] See: "Academic Spring: How an Angry Maths Blog Sparked a Scientific Revolution". *The Guardian (UK)* 09 April 2012; "Elsevier Boycott Gathers Pace: Rebel Academics Ponder How to Break Free of Commercial Publishers". *Nature* 09 February 2012.

[69] See Gibbons, 1999.

[70] Vijay Govindarajan, quoted in *US News and World Report*, 23 September, 2010. *How Netflix (and Blockbuster) Killed Blockbuster. See also*, Govindarajan, Vijay and Chris Trimble, 2010. The Other Side of Innovation: Solving the Execution Challenge. Harvard Business Press.

> Analyses of the power of biomarkers to identify high-risk individuals are worthwhile. However, measurement of some of the suggested biomarkers is costly, and therefore, efforts toward a careful comparison and appraisal of different methods to predict diabetes risk have to be made. Also, diabetes risk screening is still hampered by a large number of false-positive screening results at acceptable sensitivities and consequently by large numbers needed to treat with lifestyle interventions. Thus, new prediction models should aim to optimize discrimination rather than to replace existing models. (Rathmann, Kowall, Schulze 2010)

The authors contended that the Tethys DRS model would produce upwards of forty percent false positives. The Framingham, Cambridge, and German risk models where seen as statistically superior. They also doubted that a risk model which does not take into account smoking status, sex, and hypertension could in any way prove superior to existing models (Rathmann, Kowall, Schulze 2010: c28). Moreover, unlike the authors of the DRS literature, Rathmann, Kowall, and Schulze had no professional conflict of interest or affiliation with any commercial concern. In contrast, while the original 2009 Tethys paper was co-authored between Tethys scientists and shareholders, the 2010 response to Rathmann, Kowall, and Schulze was written solely by Tethys scientists and Inter99 Danish researchers.

> Rathmann, Kowall, and Schulze suggest that the diabetes risk score (DRS) model is no better than simple clinical models and thus is of limited utility. To support this contention, they compare our area under the receiver operating characteristic curve (AROC) with those reported for different models. However, the AROC of a test is population specific; therefore, comparisons between populations with different baseline risks are problematic because sensitivity and specificity are subject to alteration by disease prevalence.[71]

The Tethys authors argued that while the evaluative standard employed by Rathmann, Kowall, and Schulze was population specific, comparative analyses between populations was problematic. Their response to the German group was that diet and lifestyle criteria from the Danish Inter99 cohort were "unavailable," and that sex, smoking, and hypertension did not "improve the performance" of the DRS. As such, they maintained that DRS technology should not be compared with the German DRS (Moler, Urdea, McKenna, and Kolberg 2010: c29).

Therefore, the larger sociobehavioral, environmental, and community factors potentially shaping Type 2 diabetes prevalence and causation were elided in favor of biological markers of risk attributed to different subpopulations. In effect, Tethys researchers envisioned different populations with different Type 2 diabetes baseline risk profiles offering more predictive power

[71] Moler, Urdea, McKenna, and Kolberg 2010. Development of aType 2 Diabetes Risk Model From a Panel of Serum Biomarkers From the Inter99 Cohort: Response to Rathmann, Kowall, and Schulze. *Diabetes Care* 33(2): c29.

than sex, smoking, or hypertensive status. Even if race was not specifically mentioned, what the authors' statement suggests are biological differences between groups, which their technology endeavors to delineate. In this way, risk and population become both relinked and rebiologized in terms of disease prevalence. And therein, I argue, lays Tethys rationale for testing its DRS instrument among African Americans.

I question whether the risk model the DRS claims to predict with objective accuracy can be representatively transposed from a relatively homogeneous Danish population onto the diverse US population. The ethnic, social, political, economic, environmental and healthcare landscapes in Denmark differ significantly from the US. Understanding this, Tethys sought to test its technology on a group of African American children and prediabetics in Oakland. But they found it bioethically problematic in seeking to test children and translationally problematic in attracting the larger community.

The case of the PreDx™ DRS represents a continuing historical and temporal shift in the very redefinition of the prediabetic state itself. From protodiabetes, to prediabetes, now to predictive diabetic risk, what exactly constitutes "Pre"-diabetes has moved even further backwards in physiological time. In collapsing diagnostic and predictive temporal frames the DRS creates new discursive and interpretive possibilities: As a "technology of representation" it highlights the ways diabetes technologies are packaged and communicated in building persuasive narratives about the structure of both natural and social worlds (Dumit 2005:95).

Innovation, in terms of DRS technology, therefore, required new criteria and biologically valuable test populations to assess the predictive power of the instrument. The translational issue, as well as its ethical counterpart, remained how to best reach and enroll these populations for the purposes of transforming an idea into income. If they cannot be accessed in the US, overseas contract research organizations stand ready to provide test subject populations amenable to diabetes research.

Tethys BioSciences eventually found a way to obtain an ethnically diverse research subject pool, a solution which repeats the oft-seen pattern of private biomarket interests building upon older state biopolitical formations and institutions. In May 2011, Tethys BioSciences announced an agreement between the company and the United States Air Force to test the PreDx™ Diabetes Risk Score and evaluate post-test motivation on select groups of former service personnel and their dependents.[72] This arguably provided Tethys with access to a significant number of US minority test subjects, for whom Human Subjects and Informed Consent protocols are less stringent than for research among lay populations, but less open to ethical scrutiny than conducting offshore trials.

However, I and the German researchers were not alone in questioning the viability of the PreDx™ DRS to gain clinical acceptance, not as an instrument, but a tool. At the California Diabetes Health Summit in Long Beach, I spoke with a leading clinical diabetes researcher and physician at a large public hospital who works with primarily low-income and minority patients.

> I would have to ask them, "Show me the money, I mean, show me the damn money! How will your risk score save me and my patients' money and improve their health outcomes? How will

[72] "Air Force to Use Tethys Bioscience Blood Test in Diabetes Study" http://www.bizjournals.com/sanfrancisco/news/2011/03/24/air-force-to-use-tethys-bioscience.html. *Accessed* April 29, 2011.

> your risk score help to arrest the progression of the disease on those with no health insurance, in poverty, and living on the environmental edge of health?" As it stands under these conditions, I struggle to help keep my patients' Hemoglobin A1C levels under 8.0; even though we know that the desired level rests at 7.0 and below. But hell, to be honest, I'd be happy if all my patients were at 8.0. That's the reality of the situation, from my experience.

I submit that innovation occurs within specific temporal and spatial contexts. Global market and demographic drivers of DRS and other biomedical technologies, in creating new medical markets based on risk, may also create new health disparities. Of particularly lucrative economic importance here are the liminal categories of diabetic risk, such as prediabetes, combined with longer standing, yet still malleable racial, ethnic, and biological risk criteria—and the new actors, markets, consumers, and practices novel expertise seeks to individualize, enroll, (re)produce, and manage**.**

In this chapter, I bring into tension the interests seeking to individualize Type 2 diabetic risk through the development of new biotechnologies, in contrast with those high-risk populations seen as indispensable to the research and successful marketing of these products. I provide room for better understanding the challenges facing biotechnology, clinical research, and public health efforts to both imagine and successfully communicate with African American communities. While planned and unplanned technological obsolescence changes with time, African American clinical research desirability remains a constant, as we shall see in the following chapters.

The next three chapters engage these discourses, metaphors, and practices of interpreting Type 2 diabetes, and the ways in which the population, health disparities, and the genome reframe and reproduce these thematic public health interfaces.

Chapter Four: Disparities: The Church, The Prison, and The Body

The biotechnology component of my research project from 2008-2009 led me in new directions, or at the very significant least, nuanced the methodological track I would take. Untangling the desires of Tethys BioSciences and other biotechnology concerns developing diabetes risk score technologies to access, recruit, and enlist racial and ethnic populations for clinical trials heightened this move. In equating categories of race with categories of risk, it became apparent that these categories of biological difference reflected categories of social inequality. Rejecting biologized ascriptions of race rendered me no analytical alternative.

Therefore, in rejecting race as biological risk, I came to embrace social inequality as the heritable engine of both racialization and biological risk production. The verticality of my project, from an STS perspective, necessitated an engagement around the health disparities in a community, which as I will show, has been historically racialized in geographic, economic, and discursive terms.

This chapter argues that inclusion based on imprecise categorical indices of race, gender, class, etc., in determining diabetic risk must broadly expand to include the discursive disparities concerning the illness. Of particular salience is the power of the venue to attract and produce stratified bioliterate population groupings as well as the modes of veridiction, or truth-speaking, within its confines.. I present *community* here as a venue, where race, culture, risk, bodies, and history remake each other in producing a social category of immense biovalue.

Sweet Salvation

> *We often forget that the rise of a church organization among Negroes was a curious phenomenon. The church really represented all that was left of African tribal life, and was the sole expression of the organized efforts of the slaves. It was natural that any movement among freedmen should centre about their religious life....* (DuBois, W.E.B. The Philadelphia Negro, 1899: 197)

Early one beautiful Saturday morning, I received a telephone call. Apparently, word had spread that I was in town and conducting research on Type 2 diabetes. Mr. and Mrs. Vitale were calling to invite my attendance later that day at a diabetes education workshop held at their church in the center of Rochester's African American community. "We would really like to see you there, James," Mr. Vitale said. "I think it would be good for you to see what is happening at the church and in the city with diabetes. It's terrible."

Founded in 1906, the congregation of Mt. Olivet Baptist Church erected a new church in 1996 which beautifully enveloped the older church in a separate wing of the building. The church, located in the city's Third Ward, which along with the Seventh Ward, was one of only two wards in the city where African Americans were allowed to reside up until the mid-1960s. These residential and environmental constraints were intensified by the growth of the African American community in Rochester during the 1950s. At the beginning of the decade, there were around seven and a half thousand African Americans in Rochester; by the decade's end, the African American population swelled to nearly fifty thousand individuals (Wadhwani 1997).

In the 1960s Rochester, like many urban centers, experienced rioting followed by white flight to the suburbs. The formerly segregated Third Ward crossed the Genesee Street border into

the 19th Ward forming what today is known as Southwest Rochester. Urban Renewal as well as Great Society programs appeared in tandem with the slow hollowing out of the downtown area, which by the 1980s was all but gutted. The economic life of the city, including its supermarkets, migrated to the suburbs. Today, even the city's main post office is no longer located within the city itself.

Further, Mt. Olivet is located in an area devastated by the demise of the Eastman Kodak Company during the early 1980s, followed quickly on its heels by the crack cocaine epidemic of the 1980s and 1990s.[73] As of 2007, Southwest Rochester and the adjacent Maple Neighborhood had a black male homicide rate seventy times the national average, outranking New York City.[74] Moreover, increased gentrification over the last two decades has occurred in the area, as urban planners and city managers, not only in Rochester but elsewhere, have decided that the best way to address crime and poverty was to build out and through these problems, dispersing the population outwards from the center city. While gentrification unofficially aims to bring more whites back into the city, many African Americans have joined the exodus to the suburbs; others have "return migrated" to the southern US.[75]

In spite of all of this, Rochester's neighborhoods and communities retain much beauty, magic, and vibrancy. Frederick Douglass lived and published the North Star in what became the Third Ward. Susan B. Anthony's house and the Frederick Douglass Museum straddle the Third Ward and the Maple Neighborhood. Rochester long served as endpoint to or way through for passengers on the Underground Railroad, old Garveyites, Black Muslims, Moorish Scientists, Baha'i's, Red Star initiates, Elks, Masons, Alphas, African Hebrew Israelites, Rastafari, Jehovah's Witnesses, and Catholics, all sharing community space with more visible and vocal Baptist, Methodist, and Pentecostal groups.

Mt. Olivet's unique historical concern for the community is reflected in its sponsoring of its annual Diabetes and Alzheimer's Awareness workshop. Also, the church sponsors the Clarissa Street Reunion and Health Fair each August. The number of African Americans in Monroe County diagnosed with Type 2 diabetes is twice that of both Whites and Latinos.[76] In response to health issues affecting the community and its members, Mt. Olivet organized eleven Health Care Teams. Each team serves as point persons for those living within a four or five zip code section of the city. They help organize medical care and transportation for those in need as well as generate interest and cooperation for Mt. Olivet's health programs, workshops, and fairs.

If their efforts were any indication of success, at the workshop I counted more African Americans present than at the ten previous diabetes workshops and classes I had attended combined. The city's former mayor and a local news anchor, both church members, gave keynote addresses on the gravity of the spread of both Type 2 diabetes and Alzheimer's disease.

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[73] When I visited Rochester in late October, 2011, it was announced that Kodak had secured a $162 million cash bridge loan to keep the company afloat. This after earlier reports that the company was headed toward bankruptcy, with Google a potential buyer: *See* http://www.guardian.co.uk/business/2011/oct/01/eastman-kodak-reports-filing-bankruptcy. *Accessed*: November 17, 2011. *Note*: Eastman Kodak Company filed for bankruptcy in January 2012.

[74] Klofas, Delaney, and Smith. 2007. *Strategic Approaches to Community Safety Initiative in Rochester, NY. Final Report.* US Department of Justice.

[75] This demographic phenomenon was confirmed by the 2010 US Census, which showed a definite movement of *African Americans* from urban to rural areas as well as to the South. www.census.gov. *Accessed* April 16, 2011.

[76] *Monroe County Adult Health Survey, 2006*. While racial categories remain debatable, it is interesting to note that *Latinos* in Monroe County have comparable T2D rates compared to *White*s, while *Latinos* in California have a T2D prevalence resembling those of *African Americans* in Monroe County. Although geographical, historical and cultural factors influence these differences, they do trouble the explanatory power of racial categorization.

They focused their remarks on the effects of these illnesses on loved ones, and the importance of increasing awareness in the community.

At the workshop, I spoke with an African American community coordinator from the American Diabetes Association about diabetes outreach in the African American community and the role of churches. Merlene alluded to the space the venue permitted in allowing the glucometer to circulate as both object and artefact.
She said,

> We had a diabetes testing workshop at a church in another part of the state and I was shocked by the number of people who tested positive for diabetes and prediabetes, but were distrustful of the medical system. Many said they only came because it was held at the neighborhood church. Realizing how many hidden prediabetics and diabetics potentially were in the community, a lay workshop volunteer from the church made me an offer: If I gave her the requisite training to properly conduct a blood glucose test, she would offer testing to the community from the church herself. Her testing equipment would be a simple glucometer with disposable test strips.

The sacralization of risk makes room for this technological intervention: Whatever the history of medicine and the African American body have produced in terms of perceived risk, can be transcended in the sacred space of the church. While the medical gaze may have shifted from the domestic to the clinical sphere, new diabetes diagnostic technologies not only give that gaze portability, but can establish it in new evaluative venues as well. It appeared that African American churches could serve a potentially new function of disciplining African American bodies as part of the larger biomedical project.

The workshop leader, however, quickly disabused me of that thought of such future inevitability with a historical corrective based on past fact. His statement made room to envision a contingent future African American medical politics containing its own historically inherent contestations of power.

Robert Mann forthrightly declared,

> I know why so many of you are here and not there at other diabetes education classes in the wider community. It's because you don't trust the message unless it comes from people who look like you (laughter and applause). Since Tuskegee, we don't trust everything coming from medicine—and this won't be easily overcome. If you want to reach people of color you have to have people of color in front of them.

In this case, transforming data into message not only required a translating social actor, but a risk-transcendent venue as well. The African American church performs a powerful role in conveying the biomedical message about diabetes and other chronic illnesses to the community. The contemporary risks attendant to Type 2 diabetes are amplified by the historical risks of being African American in a biomedical setting (cf. Harriet Washington); and even more enduring, the

ongoing history of phenotypical and biological assessments and evaluations of African American bodies since first contact in Africa (Comaroff 1985,Cf: 2007; Gould 1981).

Dr. Asela, who holds diabetes education classes as part of his recruiting efforts to enlist volunteers for Type 2 diabetes drug trials, spoke about the absence of African Americans attending his classes at the Clinical Research Center.

> I have tried many approaches over time to try and attract more *African Americans* to our classes and workshops. I know about the history of Tuskegee and understand the reticence about participation in drug trials. I'm just trying to get them to come to the classes. I have come to the conclusion that I have to directly appeal to and through the (Black) *churches* in order to create greater awareness about diabetes and interest in our work (*Speaker's* hopeful emphasis).

The workshop leader's allusion to Tuskegee, after all, was not an argument against biomedical intervention but for a phenotypically suitable representative of the intervention itself, what those in public health call *racial concordance*. The assumption being that, an African American biomedical practitioner, researcher, or ethnographer would be more ethically reliable is, however, both questionable and problematic given the fact that African Americans were complicit in the Tuskegee Syphilis Study itself.[77] The Tuskegee Syphilis Studies serves as a cautionary example of the forms of manipulation that culturally competent health care can make possible. However, I submit that what cultural competency primarily addresses are ethnic and racial categories instead of communities.

During the period of this dissertation research project, the value neutral connotation of *social diversity* in all of its political utility became overshadowed by the value laden connotation of *health disparity,* in all of its historical intransigence. This realization became more focused as I met leading researchers and scholars in the field of health disparities, minority health, and population genetics, and the biomedical history of these topical areas. I met some of the leading African American research scholars in these areas; some of whom had worked in the final stages of the Tuskegee Project.

One researcher I interviewed was clear about the relationship between Tuskegee, medical ethics, and the questionable foci of race-based clinical trials. Unconvinced about biological attributions of race, Dr. Forsett linked the past to the present.

> You might be surprised to learn that while the Tuskegee Project was indeed ethically questionable from the start, it violated no Community Based Participatory Research Protocols (CPBR), past or present. However, Tuskegee, as well as much of race based research, tells us more about "us" than it does about the patient. Such research does not reflect the society at large—what it does do

[77] Cf. Ong 1995. Aihwa Ong illustrated this tension in her article, where Cambodian refugees are treated as medically and hygienically suspect, and health care personnel, predominantly *Asian* (Chinese) American, act as conduits of state and medical power. Foucault's language of governmentality coheres here in the ways that hierarchializing, through new techniques of the body create new biocitizen-subjects amenable to emotional and mental patterning through biomedical discourse, pharmaceutical intervention and the suppression of memory and identity.

> is give us something to publish—garbage in, garbage out. In the meantime, very little has changed. The disparity between *Black* and *White* infant mortality in the United States has not changed in over one hundred years. Health outcomes are the best indicators of social failure. Whereas one hundred years ago it was "*White*s only," today it is "insured only." But the racial disparity fault lines remain intact.

Nevertheless, or perhaps as a consequence, African Americans remain biologically valuable to researchers. I repeatedly heard from many diabetes researchers, clinicians, and medical device and diagnostic company representatives of the continuing challenges they face in recruiting African American volunteers and enlistees for their various Type 2 diabetes projects. As we have seen in Chapter Three, one biotechnology company believes that testing their new diabetes risk prediction technology among African Americans will give greater scientific and market credibility to their product, which until recently has only been tested among a relatively homogeneous phenotypical group in Northern Europe.

Race has become a privately financed object of scientific practice and technological innovation socially informed by the political and cultural practices of the neoliberal state. Research and clinical practice, arguably, say more about "us" than "the patient" or the illness. Or rather, in anthropological terms, the epistemic basis of the cultural competency model assumes rather stable frameworks of kinship in addressing the health disparities which make elusive a truly inclusive medical citizenship. The *gesellschaft* of contemporary diabetes, however, militate against any assumptions of kinship stability and social cohesion.

I argue that the very idea of *diversity* relies on essentialized notions of the constituent members of its rainbow. For example, I found that nutritional discourses and practices differed in interesting and provocative ways in the two African American communities in which I conducted fieldwork, separated as they are by thousands of miles. In New York, the *African American* community I researched consisted of both patients and diabetes professionals from the United States as well as the English, French, and Spanish-speaking Caribbean, and West Africa. In this particular African American community, diabetes educators routinely listed and mentioned tropical foods in their English language diabetes nutrition presentations. Of further interest were the various entreaties to audience about the unreliability and potential danger from using "bush" or herbs in attempting self-treatment for diabetic symptoms.

In toto, this putative contemporary US *African American* community in New York is itself a combination and permutation of individuals, couples, families, and kinship networks extending to and from the southern US, the Caribbean, Canada, the United Kingdom, France, and Africa. The African American community consisted of multiple communities. It is an emergent iteration Paul Gilroy's (1997) Black Atlantic in a truly transnational, cultural, and familineal way. In terms of this research, practices, as modes of cultural transmission, can circulate in various forms through the most contingently labeled and self-identified subjects, such as *African Americans, Jamaicans, Nigerians, Dominicans, Haitians*, etc.

However, although diabetes technosocialization exists within both the arcane social space of the church and mundane social space of the clinic, it is not clear whether the same phenomena are emerging within *profane* social spaces, those spaces which people of propriety, proper upbringing, and professional reputation reject. Outreach efforts about diabetes and its associated risk factors face the challenge of successfully targeting, specifically the younger generation and

the educationally impoverished who don't go to church, are without health insurance, or are one of the remaining six thousand employees of Eastman Kodak Company.

For example, Dodani and Fields (2010) conducted a community based T2D behavioral intervention program in an Atlanta church. Using the historically high social capital possessed by African American churches in the South as a recruiting magnet, the researchers cited a five percent loss of baseline bodyweight in forty-eight percent of the participants. However the number of participants (41) were skewed by gender (35 females, 6 males) and age (average age, 46), highlighting my concerns about the imagined research value of African American churches in reaching a more representative sample of the population. It does, I argue, point to the institutional value of African American churches in communities with few to no other comprehensive institutional bases in these communities. Interestingly, while stressing the need for creating mechanisms (admittedly unknown) to attract African American males, no mention was made of the need to attract at risk youth as well (Dodani and Fields 2010: 470-471). Therefore in terms of the therapeutic potential of the venue, the intergenerational value of these churches remains contingent at best. However, depending on changing social interpretations, the symbolic value of the African American church may become a "model for" (Geertz 1973) new biopolitical and biomarket entreaties of future inclusion and participation.

One must keep in mind that the "Black church" (like diabetes research and educational institutions) is stratified by age and gender in ways exclusive of those younger, overwhelmingly male members of the community peripheral to church participation. That said, no program I was involved in during my course of research existed which successfully brought youth and young adults into these Type 2 diabetes outreach efforts. As mentioned in the introduction, the population of hidden or undiagnosed Type 2 diabetics in Oakland, for example, is enormous—even more so when one considers the numbers with either or both chronically unchecked hyperglycemia and prediabetes. However, more African American males with hyperglycemia are being brought under medical surveillance and effective blood glucose control through the criminal justice system (Clark et al 2006).

Nevertheless, there were unforeseen but welcome responses to both my participant observation at the African American diabetes education classes and workshops; as well as interest in my larger research project. At the church workshop in New York, I discovered the most open, friendly, accessible group I met during my research period of engagement. I was repeatedly told (and since) by African American diabetes educators, patients, ministers, and physicians (on both coasts) of the need for, to paraphrase, "more black expertise in this area," and; "We need more people like you doing this work."

In New York, there was frustration with the local medical university and teaching hospital, located right across the Genesee River from a large African American community and less than a ten minute drive from Mt. Olivet Baptist Church**.** Merlene, for example, observed that, "They like to invite the community up (to the university) to basically say, 'This is who we are and this is what we have.' They need to work much harder on improving their community outreach efforts."

Both Rochester, New York and Oakland, California are "America 8" zones – predominantly African American urban areas, where both "race" and urbanity can mean dying twenty-one years earlier than an Asian American female living in "America 1" (Murray, Kulkarni, and Michaud 2006). Those transatlantic, diasporic, and intracontinental movements of Black people seeking "the warmth of other suns" (Wilkerson 2010), found themselves, like my grandparents and other family, living in "America 8 zones" such as the Third and Seventh Wards

of Rochester, East or West Oakland, or Bayview-Hunter's Point in San Francisco. It was scarcely imaginable that these urban areas would prove more deleterious to African American health than in what was then the Jim Crow rural southern US, or "America 7" (Murray, Kulkarni, and Michaud 2006).

Merlene sees the vast challenges facing public health outreach toward historically segregated urban communities of color. Despite her position with the American Diabetes Association and years of experience with both diabetes clinical research and community/patient outreach efforts, Merlene is not a Certified Diabetes Educator.
For this she says she has received some pushback.

> No I'm not a CDE, but I continue the work. I ask the Certified Diabetes Educators who have a problem with this several questions: One, why don't I see you in the communities that I work with? Two, do you understand, know how to communicate with, and make comfortable the one *African American* who shows up to your diabetes education class? Do you understand *where they are coming from*? (*Speaker's* emphasis)

Merlene's pointed questions about the relationship between clinic and community raises the issue of developing biocommunicable fluency in comfortably moving between and among different sociocultural registers without judgement.[79] According to Merlene, not only were the CDEs missing in action, but when found, lacked the cultural and racial sensitivity to make a community-wide difference. Therefore upon a closer read, Merlene's questions interrogate the *where* of diabetes outreach as much as about *who* or *why*.

The Centers for Disease Control (CDC) now recognizes the importance of understanding the communities within which obesity, Type 2 diabetes, and other cardiometabolic disorders arise. The Ecological Model, an outgrowth of the Healthy People 2010 program placed too much focal emphasis on individuals instead of communities; the point being that individuals are inseparable from communities.[80] Previously, the CDC's Community/Clinical Partnership Model framed community and clinic as separate sectors.

There were unexpected outcomes of my work among Type 2 diabetes patients and interactions with Mt. Olivet Church staff as well as diabetes researchers and educators in the African American community. I felt like a knowledgeable guest and community resource in contradistinction with the interloper/ethnographer/ guise I felt in other field settings and groupings. Joyfully absent were the palpably tentative welcomings of the African American researcher piercing through and perceiving the internal vulnerabilities, frailties, uncertainties, and metabolic dysfunctionalities of the mainstream Type 2 diabetic social body.

And what then, of the social body? Is there a social body or/and are there *networked bodies*? Thinking through these fieldwork experiences led me to question the social body, not as a social fact or theoretical given, but as a contingent formation. What was made clear to me, however, was that the problematic of health disparities, as exemplified in the case of Type 2 diabetes, remains embedded within modes of inclusion and exclusion based not *primarily* on race, but through the venues in and by which discourses and bodies are organized and engaged,

[79] *See*: Briggs and Hallin 2007
[80] *See*: Scott and Wilson 2007

the *where* of it all. Much like the balkanized assemblies protesting President Barack Obama's health care plan in 2009-2010, the venues created by those covered by insurance, such as diabetes education classes in private hospitals in contrast with those efforts conducted by local public health organizations, reflect the demographics, economics, and politics of inclusive medical care.

For example, one evening after a diabetes education class in New York, I attended a lecture at a local suburban high school presented by Dr. Neal Barnard of the Physicians Committee for Responsible Medicine (PCRM). The PCRM advocates a vegan diet high in complex carbohydrates in the treatment of Type 2 diabetes. In 2010, Dr. Barnard was featured on the Public Broadcasting System (PBS) in the United States, where he outlined his program and book.[81]

Arriving late due to attending the earlier class, I found a parking lot full of cars. My enthusiasm piqued, I entered a packed high school auditorium of perhaps one and a half thousand people. I was the only African American present. Granted, advertising for the event was broadcast on local media; however, I found myself quite stunned as to the discrepancy between message and target populations of risk. Dr. Barnard's message, excepting his book, required no massive transfer of capital, but involves new ways of eating and being in the world which actually may reduce the costs of obesity and Type 2 diabetes in the long run.

For although Barnard's presentation was no more than a fifteen to twenty minute drive from communities of color with the highest risk for Type 2 diabetes, mass transportation would have required upwards of an hour and a half to two hour commute. Mass transportation at night, post-event, would have been an ordeal. My mental scales of justice astonished me in declaring this a *disparity*. A disparity of space, access, built environment, transportation infrastructure, of opportunity.

However, I subsequently learned that local PCRM physician/patient/client networks exist in many parts of the United States and that most of those present had been contacted, formally and informally, through this network. Several months later, I located a video of PCRM's work with the large African American community in Atlanta, highlighting the success stories of former Type 2 diabetes patients who reversed their diabetic status and no longer take medication for the illness. Interestingly, the physicians in the video were themselves African American.[82] While disparate in their narrative, racial, therapeutic, and geographic disparities, the Rochester/Atlanta PCRM dichotomy illustrated the importance of not only the message, *á la* Robert Mann, but the messengers and networks conveying both concept and practice.

During the course of this research project, I worked with three Registered Dieticians who were also Certified Diabetes Educators (RD, CDE). All three are White females. Two of the three dieticians are vegan, are diabetics, and both live and work in California. The third RD, CDE, in New York, is neither diabetic nor does she exercise on a regular basis, and would be considered clinically obese. The two California RD/CDEs both maintain active exercise programs and openly shared, without proselytizing, their status as vegan in their diabetes education classes. One works in a private hospital whose diabetes education classes are paid by

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[81] *Dr. Neal Barnard's Program for Reversing Diabetes: The Scientifically Proven System for Reversing Diabetes without Drugs*. Rodale Books, 2008.

[82] See: "Physicians Committee for Responsible Medicine Diabetes Success Story Vance Warren**"** *YouTube* http://www.youtube.com/watch?v=HpO0JJToQlY. *Accessed*: 3/24/11.

private insurance, the other works for a department of public health, teaching classes among the uninsured. For them fat, particularly saturated fat was the major culprit. Given that the majority of diabetics die from heart disease and the American Diabetes Association and American Heart Association's diet and exercise recommendations have become relatively indistinct, the vegan dietician/diabetes educators with diabetes have made the decision to forgo animal fat in their respective diets. They made it clear that they were in the minority with respect to other RDs/CDEs, even those with diabetes. Merida said, "I don't know if it's a California thing or just about individual choices. But no, vegan or even vegetarian RD/CDEs are a small minority."

While eliminating or reducing animal fat may indeed prove a desirable, even necessary goal, there are larger socioeconomic factors at play. The geometer of obesity and Type 2 diabetes cannot elide the historical interplay between race and class, social distance, market economics, citizenship, and epidemiology. One symbolic venue of the Civil Rights Movement serves to powerfully illustrate this historical narrative. It is a social narrative of political and I argue epidemiological, consequence.

Counter-Public Equality: Consumer Citizenship and the Creation of a Racialized Risk Category

> *The Student Leadership Conference made it crystal clear that current sit-ins and other demonstrations are concerned with something much bigger than a hamburger or even a giant-sized Coke. Whatever may be the difference in approach to their goal, the Negro and White students, North and South, are seeking to rid America of the scourge of racial segregation and discrimination—not only at lunch counters, but in every aspect of life.*

"In reports, casual conversations, discussion groups, and speeches, the sense and the spirit of the following statement that appeared in the initial newsletter of the students at Barber-Scotia College, Concord, N.C., were re-echoed time and again:

> *'We want the world to know that we no longer accept the inferior position of second-class citizenship. We are willing to go to jail, be ridiculed, spat upon and even suffer physical violence to obtain First Class Citizenship.'* (Ella Baker 1960)

From February-July 1960, African American students from North Carolina A&T University staged a sit-in at the Woolworth lunch counter in Greensboro, North Carolina. They determined to sit-in and protest, demanding their rights as citizens to be served. The sought after commodities in question: hamburgers, fries, and Coca-Cola. In a sense, as US citizens, they sought to demonstrate form of public equality through the economic transaction. I would argue here that they sought to publically consume the symbolic *All-American meal*.[83] This meal did not originate in the domestic sphere, but the market sphere.[84] I must make clear that my intention lay

[83] Cf. Geertz 1973

[84] The hamburger, carbonated soda, Juicy Fruit gum, Cracker Jacks, as well as Aunt Jemima Syrup, all made their first appearance at the Columbian Exposition and World's Fair of 1893 in Chicago, the showcase for a new era of marketized modern urban consumption.

not in a critique of the food itself, public access, or the student protest strategy. But I will argue that as a sociopolitical venue, the market sphere offered a greater possibility for citizens to break bread, or rather, buns, together than the domestic sphere, arguably, still struggles to achieve.

National scrutiny and mounting retail losses eventually forced Woolworth's hand. In July 1960, the company relented, allowing the racial integration of its lunch counter. Since then, the market has created integrated public eating spaces in ways in which the social still has not. Spaces produce relations of affect through the sentiments they generate. In the case of the Greensboro Woolworth, forcing the hand of history created both welcome and unwelcome change: The redevelopment of the downtown area during the Urban Renewal Program of the late 1960s and 1970s signaled, as elsewhere, the demise of the central city and the rise of the suburbs; by that time, Woolworth's was one of few viable businesses left in the downtown area and it's lunch counter became known as a convenient, integrated public space (Kowal 2004: 146).

Earlier during the lunch counter sit-in, a Greensboro Daily News editorial hit upon a then neglected solution to the protesters' demands which I submit became the inclusive secret to future economic success and privatization of the public sphere: "*If the management had welcomed the handful (only three or four) on the first day and given them double portions of everything, they would have departed happy*"[85] (Kowal 2004: 142, *my emphasis*). Kowal subsequently asked, "Did the editors really believe that segregation and the protests against segregation would simply go away, as if protesters' desires could be sated with extra food?"

I respond by arguing "no" in the short term, "yes" in the longer term, which includes the present metabolic moment, in supporting my larger argument that communities based on race are sociohistorically formed and not biologically determined. Yet as Kowal pointed out, the Greensboro Woolworth's became an integrated way station in the wake of the further fragmentation, or segregation, of White and African American populations into separate suburban and urban neighborhoods. However, this spatial segregation was to last nearly forty years, throughout the period of the obesity and Type 2 diabetes epidemics, until the end of the of the twentieth century, when urban minority populations increasingly began moving to suburban and rural areas. This trend continued during the first decade of the twentieth century. So while public eating spaces have been integrated for the most part, residential spaces have until recently become more economically and spatially diffused. Nevertheless, media penetrate these diffuse locales, creating increasingly shared desires and appetites in outwardly dissimilar communities. I seek to bring attention to the exclusion and inclusion of these communities into affective forms of consumer citizenship and the media technologies facilitating these entreaties in ways non-existent in 1960.

In 1983, George Ritzer perceptively located in the fast food restaurant "an exemplar in future developments of rationalization." He defined *rationalization* as a form of "efficiency, predictability, calculability, substitution of non-human for human technology, and control over uncertainty," promised and diffused through both schools and the media. The unavoidable outcome of rationalization, Ritzer argued, and I seek to demonstrate here, is irrationality itself (Ritzer 1983: 100-101).

Fast food commercials today display a procession of multicultural youth, rappers, young urban, black, multicultural, and gay professionals (Yuppies, Buppies, Muppies, and Guppies), athletes, and ostensibly caring parents portraying a form consumer citizenship based on an

[85] *Greensboro Daily News* 1960b:A-8.

assurance of equality, quality and quantity through the venues provided by nationally franchised eating establishments. The historical struggles to obtain these assurances were hard-won and not to be given short shrift. On the ground, these consumer eating venues generate new forms of affect and meaning not easily amenable to 'rational' analysis and programmatic dietary public health interventions. I would submit that the symbolic capital of the All American meal fought for and gained by African Americans as part of the social contract has now been extended to and is valued by immigrants as well.

However, managed efficiency of service enabled by impartial technologies and the guarantee against the historical and regional uncertainties of equal treatment in producing calculable profits, figure prominently into the rational acceptance of fast food and other marketed forms of consumption. Like good private sector science, the production and performance of technologically efficient fast food service must in the end be predictable, repeatable, and profitable. The irrational social outcomes of this political economy of fast food consumption Ritzer outlined in 1983 reverberate today in the form of obesity, Type 2 diabetes, and other cardiometabolic illnesses.

Further, minorities and women have risen over the years to become chief executive officers of a number of fast food and soft drink companies, lending further credence to Foucault's insistence upon intergenerational rather than phenotypical embodiments of dominating power and control.[86] The first African American millionaire in Rochester was the owner of a local McDonald's franchise on West Main Street, which no longer exists. I remember this achievement counted as a source of pride in the African American community. These professional and economic accomplishments continue to instill pride within various quarters of a very diverse community.

Therefore, public health and translational medicine have a symbolic mountain to climb—and this includes the Physician's Committee for Responsible Medicine (PCRM). While consumer behaviors might not hold up to rational class, gender, or immigration studies analyses, they inform what these analyses cannot change and must admit—that affective practices are informed as much as they are formed. The rationalities of the margins and the marginal are often quite rational after all. However, what cannot be argued against are the ways in which these rationalities serve to redefine and reconstruct marginality, the margin, and the marginal.

Nevertheless, the problem remains that of obesity and Type 2 diabetes amongst these very populations. Given the agitation of the civil rights movement by its relatively thin and aggressive protagonists, one wonders just what biopolitical work market-induced obesity does in producing affective forms of (African) American citizenship through the economic transaction.[88] I argue that the bread and circuses of market-induced obesity and its concomitant inertia beg a political economic analysis. By analytical extension, the historical vitality of many contemporary social movements could be profitably examined through the lens of obesity and raises questions

[86] Herman Cain, the embattled Republican primary candidate for the 2012 Republican presidential nomination, was a former Chief Executive Officer of Pizza Hut, Inc., and the National Restaurant Association.

[88] As an example of the degree of influence fast food consumption as a cultural activity has changed dietary practices, seventy-five percent of *African Americans* surveyed in California cited the unavailability of fresh fruits and vegetables in *fast food restaurants* as the reason for not consuming the recommended daily amounts of these foods. See, *California Dietary Practices Survey, 2003*. Sacramento, CA: Cancer Prevention and Nutrition Section, California Department of Health Services. Cf. Bahr, 2007.

about the biopolitical possibilities of consumption in mystifying the undercurrents and shadow sides of democracy.[89] [90]
Perhaps William Shakespeare best described the political utility of obesity:

> Let me have men about me that are fat;
> Sleek-headed men and such as sleep o' nights;
> Yond' Cassius has a lean and hungry look;
> He thinks too much: such men are dangerous.
>
> *Julius Caesar* (1.2.192)

The farm policies ushered in by the Nixon Administration in the early 1970s brought about an era of superabundant food supplies at cheaper prices, made possible by government subsidies and the rise of large-scale corporate agriculture. Enabled by high corn yields, high fructose-corn syrup appeared in the mid-1970s. Beginning in the early 1980s, the obesity rate in the United States began its thirty-year climb. The next two sections explore the topic of obesity and the ways in which it has socially insinuated itself both into public health and public life.

Obesity and the Public Health of the Social Body

"The narrative of risk is the narrative of irony" (Beck 2006)

Biopolitical engagement with biopower through the public health system presents significant challenges, not only in the broad area of biosecurity, but also to our specific concern, that of Type 2 diabetes. The public health system is charged with reaching out and providing services to everyone, particularly those with limited literacy skills, and economic or social disadvantages. For the purposes of our discussion, what is important are the institutional conduits by which calculable risk is estimated and addressed through the dual logics of prevention and care among differently imagined subpopulations within the population.

Under the auspices of the Department of Health and Human Services (HHS), the Surgeon General directs one biopolitical arm of the federal government through a nationwide network of sixty-five hundred public health officers. Also under the HHS, the Centers for Disease Control (CDC) functions as the biosecurity arm of the federal government: Infectious disease, epidemiology and surveillance, disaster preparedness, environmental health, and (interestingly) tribal health fall under its purview. In addition, the CDC serves as the governmental site of clinical medical research translation in formulating future public health policies promoted by federal, state, county, and city departments of public health, their institutions and licensing organizations. Its Division of Diabetes Translation (DDT) oversees clinical translation of diabetes science—from both the public and private sector. Further, the DDT's medical translation role informs the policies recommended and programs promulgated by the Office of the Surgeon General.

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[89] The "Occupy Wall Street" phenomenon promises to give a glimpse of just how vital the body politic remains. One protester's placard "I will not Work, Consume, and Stay Silent Anymore," illustrated an awareness of the intersections of biopolitics, biopower, the market, and the political limits of gustatory bribery.
[90] Cf. Berger, 1972. Ways of Seeing.

I participated in a conference, "Diabetes and the African American Community," organized by the Santa Clara County Department of Public Health. The keynote speaker, former Surgeon General Jocelyn Elder, described her experience with Type 2 diabetes. Being diagnosed with the illness forced her to reckon with and reconcile the discrepancies between her professional role as the nation's top public health officer with the necessary practices around diet and exercise that can prevent and control the illness. Admittedly overweight, Elder struggles with balancing health and professional demands. She is not alone. The conference was remarkable in many ways, most notably in the number of obese public health officers, predominantly African American, present. So many that, after lunch, the conference facilitator chastised the participants for not practicing what they preach. She immediately requested that everyone, including the former Surgeon General, stand and spend a few minutes performing light calisthenics in place before continuing with the conference. Double-breasted suits swayed, gold buttons flashed, and shoulder pads lifted. Pure penance.

Some months later at a health disparities conference I reconnected with a physician who had been present at the San Jose meeting. A former college basketball player, she had recently been appointed to work in the Obama administration, helping to spearhead a program begun by the First Lady aimed at increasing physical activity and improving healthy food choices amongst the population. I asked her about that moment of calisthenic penance at the San Jose meeting and the apparent disconnect between professional health practitioners and the professional health recommendations they give to both patients and publics.

She remarked,

> I can tell you now that it is very rare to find medical and public health professionals who practice what they preach. In the beginning of my career, I too was surprised to see this in my travels around the country. To be honest, the only group where I have found health professionals walking the talk has been in the physical activity community itself.

What is important to point out here is that the logic of care does not translate neatly into the logic of choice, much less the logic of practice (Bourdieu 1977, 1990; Mol 2008). As such, both dissonant incongruencies and coherent rationales co-exist even within those charged with implementing and deploying these very logics in their own imagined communities. However, to be clear, I found obesity amongst health care professionals of all backgrounds during the course of this research. The message and messenger disconnect is socially wide and demographically deep.

Bodily Factors

"If they had been hogs, they would have been ready for slaughter."[91]

This section explores the ways in which culturally appropriate techniques of the body have changed over the last quarter of the 20th century and into the twenty-first. It engages the role of technology in reconfiguring the notion of bodily discipline through language, discursive circulation, and affect. More precisely, this section interrogates the ways in which technology both enables and constrains agency, and the gendered and hierarchalized forms of representation

[91] David Bragi. *Our Pursuit of Pleasure is Endangering our Health*. SF.Gate 10/29/2001

this sometimes takes. It is a narrative of the causal metaphors informing Type 2 diabetes emerging from within the contemporary phenomenon of obesity.

This section's epigraph quotes an individual, admittedly forty pounds overweight and diabetic. He directed his remarks toward the human panorama he witnessed while at Great America amusement park in Santa Clara County, California. Visual evidence of the obesity epidemic in contemporary US and cosmopolitan societies has approached the irrefutable. Darlene, who lives in a relatively affluent and isolated San Francisco Bay Area community, said that the fear of crime as reported throughout the media has had the chilling effect of dissuading parents from allowing their children wider spatial latitude in which to run and play. According to Darlene, such fear has influenced some adults' willingness to walk the streets for exercise. "Even the adults say they aren't comfortable walking in their own neighborhood. They see the potential for crime everywhere, although *nothing* happens here."

There was a time when children played outdoors, all day, nearly every day, spontaneously; rarely organized, and often unchaperoned. Today, children are rarely seen climbing, much less seasonally anticipating, trees laden with ripening fruit. Too risky.[92] Today, playgrounds are relatively empty. In inner city areas such as Bay View-Hunter's Point, West Oakland, and Long Beach, as well as the valleys of inland California, environmental hazards increase the risk of developing asthma for those either foolish or happy enough to have the temerity to attempt playing outdoors for extended periods of time. Violence, for long a blight upon many neighborhoods, has over the last twenty or so years, forced more young people indoors than might have otherwise. No one talks about midnight basketball anymore. A 2004 study concluded that on average, an *African American* adult in Los Angeles exercised about ten minutes per week. Both the American Diabetes Association and American Heart Association recommend between 150-180 minutes per week of *aerobic exercise*.

One the other hand, the preceding description is somewhat misleading. Violence has been a part of inner city life for decades, long before the explosion of Type 2 diabetes in the US. The increased sedentism we have witnessed over the last few decades extends to all communities, in all regions, environments, and socio-economic classes. Playgrounds are also relatively empty in wealthy areas such as Palo Alto, Atherton, Los Altos, Brentwood, and Marin. Type 2 diabetes is no longer an epidemic—it has become arguably both endemic and pandemic as well. However, the severity of its intensity is experienced most acutely within minority (African, Native, and Mexican American) communities. In terms of both risk and prevalence, the question, in both conceptual and methodological terms, is how environment, genetics, or practices inform pathology. While it can be profitably argued that environmental and even genetic changes are possible within short periods of time, it could be equally argued that human practices and other material engagements effect change rather quickly as well. In 1999, the Diabetes Prevention Program Research group stated that the multiplicity of genetic and socioeconomic factors

[92] This technocultural shift is laid bare by the ironic fact that upwards of two to three million fruit trees were destroyed in the Santa Clara Valley in the development of Silicon Valley. For a satellite view of some of these former orchards on present high tech sites, *See*: http://google-latlong.blogspot.com/2010/12/rediscover-historical-imagery-in-google.html. This horticide is comparable to George Washington's punitive raids against the Seneca, Cayuga, Onondaga and other Iroquois Nations for either maintaining neutrality or siding with the British during the Revolutionary War, after which millions of peach, pear, cherry, apple, and plum trees were destroyed in Western New York State. *See*: Wallace, A.F.C. and Steen (1970) *Death and Rebirth of the Seneca,* pp. 141-145). It is perhaps of no small coincidence that both these historical areas of horticultural destruction exist geographically within and adjacent to the areas of this dissertation research project.

accompanying Type 2 diabetes made it impractical to design interventions to address them all (1999: 630).
The authors went on to conclude,

> Obesity and physical inactivity are potentially modifiable risk factors for Type 2 diabetes. Modifying them, however, is very challenging, and it has not been clearly established whether such modification reduces the incidence of diabetes. Insulin resistance and impaired insulin secretion, the metabolic defects predicting Type 2 diabetes, can also be treated pharmacologically. The hypothesis that such treatment can prevent diabetes has not been adequately tested (1999: 631).

I find it interesting that the authors implied that intensive lifestyle change, although challenging, could potentially *modify* T2 risk factors but that pharmaceutical drugs could *treat* "the metabolic defects predicting T2 diabetes." The generous certitude of the latter statement was not extended to the former. Any benefits arising from intensive lifestyle modification would have to be "established" through incidence reduction criteria while pharmaceutical therapy only has to be "tested" against its own hypothesis. The dire consequences of the latter pharmaceutical premise, built into the original Diabetes Prevention Program methodological framework, resulted in the elimination of fourth control group after one of its members died of hepatic failure as member of the Troglizatone control group. Despite this, the authors, I suggest, go on to present pharmaceuticals in the language of rational therapy devoid of the social, cultural, and environmental problems or challenges facing the *latent* diabetic. The socioeconomic and genetic factors that make diet and lifestyle therapeutically challenging obviate the fact that pharmaceuticals cost money and exercise is free.

I argue in this section that new forms of human technological engagement have influenced social and cultural attitudes toward the body and movement. I show how these attitudinal shifts toward manifesting increased physical inertia have been naturalized and rendered invisible, complicating and potentially confounding obesity and Type 2 prescriptions, plans, and policies. It is into these milieux that the DRS seek to enter and play a role.

On a San Francisco Bay Area blog fielding responses to the announcement of the development of the DRS, a local physician wrote about the sociocultural attitudes shaping contemporary obesity and the possibility of technological interventions evoking a moral economy of rational patient action, saying

> A new test is not going to matter that much—as an internist (doctor for adults) who specializes in diabetes and HIV care, I can tell you that when it comes to diabetes and pre-diabetes, the writing is usually on the wall—we already can tell who's at risk, and we counsel them, but they don't change what they're doing. We tell patients that they should be doing the equivalent of jogging 7-12 miles weekly, and eating better. Most of them won't. Americans have made "normal" a profoundly abnormal, inactive lifestyle, and they eat many processed "foods" that should never enter one's mouth. So of course they get diabetes. China just finished a huge,

> 20-year-long study showing that healthy diet and exercise can cut the rate of diabetes almost in half. Expensive tests won't make the difference here. The health habits should already be in place. Maybe a new test will be a stronger motivator, but I'm dubious.

Technological advances over the last twenty-five years—from the Mac, to video and computer games, to an array of mobile devices—have coincided, rather suspiciously, with the rise in Type 2 diabetes. The epoch under examination also heralded the demise of physical education classes in schools around the country; today, even recess is under threat.[93] This period has also witnessed the marketed rise and social acceptance of fast food. It also witnessed the symbolic sacralization of pizza, the mall, and the movie into a new form of ritual pilgrimage among the Nacirema.[94] The food/event/appropriateness social metronome today beats to an entirely different rhythm.

Exercise, too, is undergoing a change in nomenclature reflecting both its historical associations and contemporary meanings. *Activity* is the new word in vogue, replacing *exercise*, relegating the notion to the Fordist past it occupied with older terms and epistèmes, such as *fitness* (Rose 2007) and *training* (Martin 1994). Of particular note is the way in which activity is interpreted as connoting a form of self-agency that exercise does not.

A public health nurse and diabetes educator in Rochester said she no longer uses the word *exercise*,

> …because it just puts people off. They equate exercise with a routine, an imposition, something they have to eventually become good at in order to be successful. It sort of suggests that you're not good enough when you begin. I prefer to use the word *activity*, in (both) my talks and informational materials."

In fact, the Centers for Disease Control (CDC) created a Division of Nutrition, Physical *Activity*, and Obesity (DNPAO). The DNPAO is charged with

> ….working to reduce obesity and obesity-related conditions through state programs, technical assistance and training, leadership, surveillance and research, intervention development and evaluation, translation of practice-based evidence and research findings, partnership and development. (http://www.cdc.gov/obesity/index.html)

Interestingly, DNPAO subsumes not only exercise, but also "diet" and "program" under the organizational rubric of "lifestyle" in the hope of aligning contemporary neoliberal notions of self-agency with the epidemiological and methodological imperatives of the obesogenic and diabetogenic present.

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93 "During School Recess, New Focus on Playing Nice." *PBS News Hour*, 24 July, 2009. An Oakland, California non-profit, Playworks, offers and provides recess programs to schools nationwide in an effort to both help cash-strapped school districts and address childhood obesity. www. Playworks.org media/news/during-school-recess-new-focus-playing-nice. *Accessed*: 31 March, 2010.

94 Miner (1956).

However, fieldwork uncovered both conceptual dissonance and methodological confusion concerning the precise definitional nature of *activity* compared to *exercise*. For one, almost all interlocutors attested to how "active" they were, how their days were filled with chores, appointments, obligations, care of others, etc. and how this left little time for "exercise" as a formal practice. There were those who believed that their once or twice daily walk with the dog constituted exercise. Once upon a time, this was known as leisure and recreation. Nevertheless, the overall feeling of most interlocutors was that their lives were active, that they were active people, that they loved life. "Busyness" or "busy work" (Darrah, Freeman, English-Lueck 2007) seems to have become conflated with *activity as exercise*. Busyness/busy work as activity misrecognized as exercise not only misses the aerobic targets necessary to positively influence glucose metabolism: it also informs the comparative anatomy and physiology of contemporary stress. Stress not only increases hypertension, but blood glucose levels as well.

Although caloric consumption has remained relatively stable since the mid-1980s, obesity has risen dramatically (Philipson and Posner 1999). Arguably, however, the quality of the calorie ingested has changed as well. As mentioned previously, may be other factors at work in assessing the rise of obesity in the West, particularly the US, since the early 1980s. Robert Lustig's (2009a, 2009b) work on sugar and high-fructose corn syrup suggests that sugar, whether from cane, beet, or corn, is responsible for driving the obesity and Type 2 epidemics. The increased use of sugar, primarily HFCS, in processed foods and a low-fiber diet increase one's susceptibility to obesity. The fiber consumed when eating fresh fruits mitigate the effects of fructose on the body by slowing down its digestion and assimilation. Therefore, in Lustig's view, fat and complex carbohydrates should not be blamed for either obesity or Type 2 diabetes: attention should be placed squarely on sugar and fiber.

Significantly, Lustig's hypothesis leaves no room for implicating race or thrifty genes in examining contemporary caloric consumption and obeso- and diabetogenesis. While Neel argued that consumption of excess calories would affect a negative evolutionary outcome for the thrifty gene, Lustig presents an argument of there being a biological tipping point for everyone past which excess sugar consumption and inactivity will trigger cardiometabolic disease, irrespective of race or the thriftiness of genes.

The contemporary geometer of obesity informing Type 2 diabetes risk, occurrence, and discourse is differentially inflected not only through *race and gender*, but also class, region, educational attainment, degrees of urbanization, and levels of bioliteracy. The epidemic in obesity and resultant cardiometabolic risk is a multifaceted study in interpretive etiology—of a unique epidemiological process—of collectively witnessing an epidemic become progressively and at once, both pandemic and endemic. Obesity is a phenomenon of many colors, classes, and genders, predicated upon a political economic rationality productive of these metabolic and cultural irrationalities. While it may be causally constructed in segregated (networked) social spaces it is affectively integrated into the extra-sized fabric of contemporary citizenship. The body as representation and product of histories material, social, economic, cultural, and gendered now demands new forms of care and discipline in response to the undeniable metabolic realities concerning its very existence and purpose in the contemporary world.

Care, Discipline, or Drugs?

Dr. Asela was born and educated in Sri Lanka. He completed medical school in the US and is one of a growing number of foreign born or trained endocrinologists practicing in the United States. As mentioned earlier, this cadre of endocrinologists is part of an inadequate

solution to the pipeline problems stemming from the current lack of interest in endocrinology as a field of specialization among US medical students.

When I first contacted Dr. Asela concerning my research, he warmly invited me to meet and discuss both my project and the Clinical Research Center's work. The center's location is in a medical building in a beautiful area near Irondequoit Lake, New York. In my previous life in the area, I had never knowingly spent any time in that part of county. My sense of who I was and have become since leaving was often refracted through the rearview temporal and spatial lenses of segregation and epistemological constraint. In a real sense, the field was familiar but quite unknown.

The Clinical Research Center conducts public education classes for people with Type 2 diabetes, hypertension, gout, and other cardiometabolic disorders. As part of their public education, CRC recruits volunteers for third stage drug and other clinical trials for not only cardiometabolic but other illnesses as well. Their funding comes from pharmaceutical and biotechnology companies as well as public institutions such as the National Institutes of Health.

I spent two months with Dr. Asela in late 2008 during the Clinical Research Center's fall diabetes workshop series. We first met just before the start of the series, a quite fortunate occurrence as this gave us time to talk before and after the meetings. We sat in the center's boardroom, a large corner room with an oblong hardwood meeting table perhaps ten feet in length. All four walls were covered with blackboards and literature about the center's activities. We quickly discovered that we had much in common.

I had spent a year in India and Sri Lanka from 1989-1990, researching Ayurvedic medical colleges and pharmacies. Based in South India at the time, I travelled extensively throughout Sri Lanka— more precisely, in those areas in the south and west of the country free from the then civil war. Dr. Asela's eyes lit up when I mentioned *karwila* (*Momordica* sp., which includes bitter melon and balsam pear; *karavellaka* in Sanskrit; *karela* in Hindi; *caraille* in the Eastern Caribbean, cerasee in Jamaica), a bitter herb prescribed in Ayurvedic medicine for hyperglycemia.[95] It is also taken to reduce fever, inflammation, and obesity.

He recounted the many mornings he was forced by his mother to drink an infusion of *karwila.* He became almost wistful while narrating the use of traditional medicines in Sri Lanka. He then quickly seized hold of himself, "We must remember that traditional medicines are useful only in self-limiting illnesses; meaning, conditions which would have eventually resolved themselves over the course of time."

However, it was apparent that Dr. Asela was quite proud of both the knowledge production and practices developed in Ayurveda over two millennia in Sri Lanka. The fact that I had travelled so far to inquire about such an ancient system of medical practice in the land of his birth bonded us in an unspeakable way. Moreover, he came from Sri Lanka to upstate New York to engage in the modern practice of biomedicine and in the process became aware of the zone of health, educational, and economic disparities from which I arose and took flight. It is within this and other zones of health disparity that bedevil Dr. Asela and others seeking to reach out to at

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[95] Leatherdale et al., 1981B.A. Leatherdale, R.K. Panesar, G. Singh, T.W. Atkins, C.J. Bailey and A.H.C. Bignell, Improvement in glucose tolerance due to *Momordica charantia* (Karela), *British Medical Journal* 282 (1981), pp. 1823-1824; Akhtar, M.S. Trial of *Momordica charantia* Linn, (karela) powder in patients with maturity onset diabetes, *Journal of the Pakistan Medical Association* 32 (1982), pp. 106–107.

risk, particularly minority, communities. The following section illustrates the problematics of this outreach and the venues in which these efforts occur.

Interactive Biology

Dr. Asela opened the first diabetes education class, saying, "This is an informational group about diabetes, not a support group. I hope that this will be an interactive group also." He then told the group that out of this series of meetings the Clinical Research Center looks to recruit research volunteers for diabetes pharmaceutical drug trials. I was then introduced to the 60-75 persons gathered as a PhD graduate student from the University of California, Berkeley. Dr. Asela emphasized that my research was not connected with or financed by any pharmaceutical interests, that my presence was purely observational, and that over time, I would approach a few individuals who might be open to being interviewed by me.

Apart from an East Asian male, Dr. Asela and I were the only males of color present. I could not help but notice our contrasting roles of distanced authority and expertise. Our positionalities reflected a chimera of new phenotypes of both scientific narrative and ethnographic authority—potentially more disruptive to ways of knowing and being in the world than blood glucose metabolic numbers alone.

Dr. Asela then went over the workshop series schedule that was included in the informational packet distributed at the outset of the meeting. He further explained that the CRC conducts research into various metabolic disorders, all of which are epidemiologically interrelated. From this, Dr. Asela said that all participants/diabetics should know what the standards of care are and should be concerning diabetes. Dr. Asela then went into the physiology of glucose metabolism, beginning his PowerPoint presentation.

The audience seemed to be searching for answers and information—yet none looked as if they adhered to an active fitness program. Some could barely walk—about eighty percent of those present were obese. Except for one elderly African American female, two South Asian females, and the East Asian male, the audience was entirely White. However, the African American female recognized one of her White female coworkers from the assembly line they shared decades ago. The majority were middle aged and older, reflecting a period when manufacturing jobs in the region were plentiful and health insurance available.

Dr. Asela began, speaking about the Oral Fasting Glucose Tolerance Test (OGTT) and the numerical borders between diabetes and prediabetes. A woman raised her hand, identifying herself as a phlebotomist, saying that even sugarless gum can throw off an OGTT result. Immediately, she noticed a South Asian female colleague sitting in front of her. This, along with the example of the African American and White former co-workers, pointed to me the commonalities of diabetes—its public and the private discourses, its visibility and invisibility—without the appropriate venue enabling these acts of truth speaking in allowing for a presentation of self.

A man raised his hand, protesting, "But Dr., when I hit 110, I feel extremely lethargic." Dr. Asela responded that these borderline numbers are used for diagnostic purposes only, admitting that there are discrepancies between the numbers and lived reality. Despite these discrepancies between the borderlands of diagnostic certitude and the uncertainties of lived reality, Dr. Asela insisted that everyone get all family members and friends tested for prediabetes.

In this new interactive air of educated uncertainty arose a question from a woman asking if diet and exercise could reverse Type 2 diabetes. Dr. replied, "No, the underlying tendency (or

uncertainty?) toward diabetes will remain." Another woman chimed in that "Like my mother's doctor says, 'if you're an alcoholic, you are an alcoholic for life,'" offering support to Dr. Asela's assertion. Other interlocutors used the alcohol analogy at various times during the research period. Against this background, Dr. Asela then explained the physiology of glucose metabolism—increased blood glucose being due to glucose not entering cells for energy, resulting in the body craving water to flush the excess unmetabolized glucose from the body through the kidneys; and that consequently, one half of all renal dialysis patients are diabetic.

The grouped seemed to be quite bioliterate, or familiar with medical languages, practices, and technologies. However, I was not sure if this was due to personal experience as a patient or as a medical professional, as in the case of the phlebotomist? How does this inform their practices around diabetes?

Right on cue, just as I finished the above thought, an audience member asked about the "metabolic syndrome," only to be interrupted by the very communicative phlebotomist who proceeded to give a rundown of all the illnesses contained under the rubric of the metabolic syndrome. This was punctuated with Dr. Asela saying that "Diabetes is part of this syndrome. Ultimately, it is up to you—not your family, friends, even spouse, to manage and control your diabetes. We do research on medications, but ultimately it is up to you."

He then emphatically added, "Exercise is as good as medications—cheaper, no side effects, and it does wonders. This is my take home message to you." However, I got the impression that medications were a better sell than exercise to a large percentage of those present who seemed to have more experience with the former than the latter.

Dr. Asela then asked,

"Do any of you want to spend the rest of your lives counting calories?

The audience wearily moaned, "No!!!"

Dr. Asela continued, saying that while it is important to count calories in the beginning, eventually this can become overwhelming. "Exercise and better quality eating are the best ways to deal with one's diabetes." He informed the group to check the educational resources from their insurance companies, the main two in the area (Excellus and Preferred Care) for more guidance and information about diabetes.

At the end of the meeting, the phlebotomist nervously said "Hi." We exchanged greetings and names. Terri appeared a little over five feet in height, and easily over two hundred pounds. I asked her how long she has had diabetes.

She replied,

> I was in denial about it for years, and so was my doctor. One day I decided not to live in denial, changed doctors, and then accepted what I knew, that I was a diabetic. Although I accept the diabetes, I still live in denial when it comes to using my meter. I don't.

I then followed in stunned masquerade, "But you're a phlebotomist!" in response to which we both heartily laughed with a mutually amused unease. ….

. …On the way home, I stopped at a local supermarket at least ten miles away from the site of the diabetes education class. As I enter, I look to my right; there is the phlebotomist, holding a large three layer cake with icing standing in the midst of the baked goods section. Stunned, I quickly swerved left into the nearest aisle before she could notice me. I remain unsure as to whether I sought to avoid her embarrassment or my own. My sudden relief was punctuated by the more sober realization that diabetes can be a difficult illness to manage. While one can

live without tobacco, alcohol and (arguably) sex, everyone must eat. For the diabetic, eating presents a daily challenge. According to the FDA Diabetes Guide, "Because food intake affects the body's need for insulin and insulin's ability to lower blood sugar, diet is the cornerstone of diabetes treatment"(2007). Terri's (the phlebotomist) example and the diabetic's necessary dietary vigilance reminded me of what an earlier interviewee, David an ex-alcoholic and ex-smoker, echoed, with *le gateau aussi* on his mind:

> David :My biggest problem right now is I'm borderline diabetic, and that's a killer for heart disease, and I'm really working hard to try and do something about that. It's just gradually gotten up and up and up and up (blood glucose levels), and that stuff is like smoking. It will scar the inside of your arteries. I mean, it causes plaque to accumulate. I mean, it's just really bad news, so I've really, really got to work hard on telling myself that, too. I did some hard things in my life but cutting out carbs and cutting out calories is one -- you know, I haven't got to the point of, "Damn it, David, you've got to do this, and let's just forget about it. Just do it." But, you can't quit eating. I could quit smoking, and I can quit drinking, but you can't quit eating, so it's a different kind of habit to get rid of. [laughs] You know, that's why they say for alcoholics you don't want to go back and take the first drink, because that's going to lead to the second and the third. Well, that's like eating, right? Go have just one piece of cake, right? I mean, it's been three weeks I've been on this crazy diet of low carbs, you know? One piece of cake is not going to hurt me. Believe me, that's just as bad as the drinking. I cannot give into that impulse.

David's past ordeals with tobacco and alcohol addictions taught him vigilance and moderation. However, while many Type 2 diabetics interviewed and speaking at diabetes meetings said they ardently wished to forget about their condition and re-experience the days of carefree youthfulness, they knew about the risks involved. Several paid the price of an amputation for not regularly monitoring their blood glucose, eating on time and getting metabolically sufficient exercise, and taking medication based on the metabolic effects of the previous factors. While fieldwork at the Clinical Research Center proved rather disconcerting (as well as for Dr. Asela) in terms of anticipated African American participation, I did come away with an appreciation of the obligations and burdens facing Type 2 diabetics, regardless of race, ethnicity, or class. With this understanding I left the field in Rochester convinced that Type 2 diabetes was an equal opportunity illness and that health disparities the result of something more than biological race or genetics. I also departed convinced that research outreach to churches misses the hip-hop, rap, and swag generations entirely. Fieldwork in Southwest Rochester and at the CRC elicited no contacts with Type 2 diabetics less than forty years of age. The Type 2 diabetic field in California awaited and I began making incipient plans to meet with African American health disparities researchers at the national level.

Melvin: Homelessness, The Prison, and Control

Dressed in a light blue suit that was perhaps a little too large, Melvin stood front and center, tall and erect, with the self-dignity of someone who had survived many challenges. In his late forties, he was there to talk to the assembled, mostly public health professionals, about his experiences with Type 2 diabetes, homelessness, and incarceration. At this conference about Type 2 diabetes and the African American community in San Jose, he told a harrowing story about his life in the Sacramento Valley.

> One day I found out that my job was being terminated. After my unemployment ran out, I found myself falling behind on my rent and other bills. I had been looking for work but couldn't find anything. Next thing I knew I was homeless. The whole experience was stressful. I went from living with friends to living on the street. This got me arrested for public vagrancy. I hadn't been eating right and hadn't been feeling all that well with the stress and everything. When I went to jail, I said I didn't feel good and they ran some tests. (That is when) I found out I was diabetic and had high blood pressure.

I noticed that while Melvin spoke, holding his hands to his sides, he periodically clenched his fists as if these struggles were fresh in his mind and still yet to be completely won. Recurrent cycles of homelessness and rearrests exacerbating chronically elevated and unchecked hyperglycemia and hypertension threatened Melvin's life several times. Standing there in his oversized blue suit, he brought out the ironies and paradoxes surrounding homelessness, the diagnosis, lack of health insurance, and the role of the police, judiciary, and penal institutions to not only *control*, but to *care*.

More pointedly, what if the prison is the clinic? What forms do care and control of Type 2 diabetes take and what practices do they authorize within the panoptic clinical space of the prison? As the United States' burgeoning prison population ages, chronic illnesses such as Type 2 diabetes have become increasingly prevalent. With the majority of prisoners belonging to high-risk Type 2 diabetes minority and lower socioeconomic groups, jail can become a primary site of medical care—serving a similar diagnosis and treatment role as many hospital emergency departments. Yet, while the American Diabetes Association and the National Commission on Correctional Health Care have published diabetes management guidelines, little data exists concerning the effectiveness of diabetes care in prisons (Clark et al 2006).

Clark et al.'s (2006) research on Type 2 diabetes in the San Francisco County Jail sought to fill this lacuna of data by examining diabetes care among an incarcerated population. Finding that many diabetic inmates (such as Melvin) have high blood glucose levels at the time of booking, the authors argue for the need to quickly assess and treat these patients/prisoners. They also found that prisoners incarcerated for long periods of time achieved better blood glucose control than transient, short term inmates (such as Melvin). To address the challenge of improving therapeutic (or diabetes management) outcomes for short term inmates, the authors recommended creating a referral network from within the jail system which would link newly released inmates to community and public health diabetes programs. In effect, jail has become an important public health institution in itself for minority and poor populations, and a vital therapeutic link in the care of Type 2 diabetics from these at risk groups (Clark et al. 2006: 1573).

In fact, Melvin was connected by jail health services to a community health program serving a three county area in the Sacramento Valley. The Tri-Valley Health Care Center serves a large population of indigent patients. Ninety-three percent of its patient population present without health insurance. However, the center has been able to give Melvin a new lease on life within a socioeconomic context in which the cost of living remains high, not to mention the costs of Melvin's diabetes care itself.

As in the case of Melvin's joblessness, homelessness and incarceration, mediated therapeutic action was not the outcome of an egalitarian, but a judicial process. Melvin, by God, was inspirational in his determination to not only speak in the public sphere, but to claim it, rather than allow himself the indignities of silences produced within the twin valleys of social death of which both homelessness and prison incarceration represent. The "Valley of Death," however defined, exemplifies the space where the dual threat of risk and death uneasily co-exist with the singular promise of therapeutic hope.

For example, an inverse gender analysis of genetic testing of African Americans reveals the bioethical and legal implications of such testing. Matrifocality in Western/Creole societies is generally diagnostic of either or both male racial and class exclusion from the wider socioeconomic field (Brereton 1979). The criminal justice system as a site for the policed adjudication of this socioeconomic exclusion has increasingly become a primary site for minority male genetic inclusion (Roberts 2011). The majority of African American male DNA samples exist within the FBI Genetic Database. Comprising twelve percent of the population, African Americans, mostly males, comprise forty percent of the FBI Genetic Database. Further, DNA collecting increasingly occurs upon police intake and applied not only for misdemeanors, but also to those taken in under suspicion without charge. [96] Bioethical and legal concerns about confidentiality, anonymity, informed consent, and other Human Subjects and IRB protocols do not apply under such circumstances (Cf. Greely 2009).

While arguably such a scenario of incarceration reinforces matrifocal social structures and subjects large numbers of Black males to DNA technology, it occurs not within the context of care, but of discipline, punishment, and control. Even more troubling, the preoccupative search for genetic pathology amongst African (Americans) coupled with collection of African (American) prisoner DNA, may serve to reinforce earlier scientific notions equating blackness with deviance.

I question the viability of the church as a therapeutic magnet for Type 2 diabetes and other forms of cardiometabolic education and care in attracting the overwhelmingly younger, primarily male members of the community peripheral to church participation. I presented an example of homelessness and incarceration to illustrate how for many African American males, jail and prison have become primary institutional sites of successful Type 2 diabetes treatment. I threaded this discussion within my larger argument that race and risk co-produce each other through the categories they occupy within particular environments, at different moments. These moments pass in public and counterpublic (Warner) spaces, inside and outside of history (Wolf). Interrogating these spaces allows us to more fully understand how risk is "inhabited as a form of ruling and being ruled in the contemporary world" (Beck 2006; Cf. Bourgois and Schonberg

[96] Forty-two percent of all Black males in Great Britain have had their DNA collected and housed by the government, as opposed to six percent of whites. *See*: "F.B.I. and States Vastly Expand DNA Databases." *NY Times* April 18, 2009. *Accessed*: April 10, 2010.

2009). In the case of Type 2 diabetes, my analysis extends Beck's statement in presenting how *affect* is inhabited as a means of "ruling and being ruled" as well.

DuBois' late 19th Century functionalist description of the role of the Black church as a total institution was emblematic of the theoretical conventions of its time. However, I extended this historical lens onto contemporary biomedical visions about why, where, and for what purpose African American research inclusion carries such vital urgency. I have tried to show that the question of how to access African Americans remains an outstanding one and how, as an imagined community, diabetic risk and prevalence exists not only within the public sphere of the church, the liminally visible spaces of homelessness, but also within the counterpublic shadows of the jail and prison systems (Cf. Warner).

The following chapter examines how this imagined community figures into new genetic and genomic research. The increasing affordability of genomic sequencing technologies has created a discursive shift from risk based on membership in a racial group to that of risk based on individual ancestry. I will show how that language of race intractably survives as an organizing principle for discussing ancestry (or the perhaps more useful social scientific term, *genealogy*) analyzing kinship, broadening both surveillance and participation, and in the case of Type 2 diabetes – marking its changing significance.

Chapter Five: Health Disparities, Race and Ancestry

The first part of this chapter explores the discursive spaces in which health disparities conversations about Type 2 diabetes often become organized around biological and pharmaceutical understandings of fragmented and stratified human populations. Otherwise known as *diversity*, these fragmented and stratified populations reveal in play the political history underpinning the biopharmaceutical assemblage itself. The second part of this chapter explores how race and ancestry confound genomic understandings of difference and disease, as well as the bioethical implications of diversity outreach toward and translation of such research. I present a sketch of how the biopolitics of Type 2 diabetes serves as a useful analytical site for examining the ways in which clinical and social network data both converge and diverge.

Part One: Prologue to the Gene

Biopolitical Disparity

The Health in the Global Context Summer Workshop was held in Houston, Texas. Sponsored by the University of Texas MD Anderson Cancer Center, The University of Houston, and the National Center on Minority Health and Health Disparities, the workshop attracted undergraduate and doctoral students, postgraduate fellows, faculty and health professionals from clinical, public health, and community institutions. The Program Chair gave an inspirational opening address where he challenged those gathered to work towards a future when his grandchildren and others of color would not bear the brunt of poor health outcomes resulting health disparities based on minority status and unequal medical access.

A schedule of presentations over five and a half days included interdisciplinary panel discussions organized thematically around ethics, social and environmental justice, genomics, obesity and the effects of targeted tobacco industry penetration of minority communities. Barbara K. Krimgold, national director of the Kellogg Health Scholars Program moderated a panel of former or current Kellogg Health Scholars, mostly epidemiologists, who presented their research on health disparities. These postdoctoral fellows and junior faculty of color represented a new generation of health disparities research and scholarship.

A bioethicist presented on the ethics of health care disparities in light of ongoing debates concerning the cost of health care. He differentiated between the 'rationing' and the 'allocation' of health care, arguing that the US medical system has sufficient resources to allocate health care, but that its structure constrains access to the point of rationing health care in ways which produce exclusion and disparities in terms positive health outcomes. However, while data exists confirming the structures and processes by which health disparities are created, Michaels argued that "Data does not take into account or solve ethical and moral factors and values. It is not prescriptive – it cannot tell you what to do. Data cannot solve moral dilemmas; and it never will." Therefore, the outstanding question "What is the emotional and psychological burden of care?"

A former CDC researcher gave an excellent presentation of the history of the Tuskegee Experiment. Dr. Mardis provided both the historical and scientific contexts of the study as well as comments on the critiques of Tuskegee since its disbanding in the 1970s. He emphasized that the study was always "public" to the extent that its ongoing findings were periodically published in medical and scientific journals over the course of nearly four decades.

The workshop notably included contributions from journalists working in the area of health disparities. A former network news chief medical reporter related his experiences in medical journalism, most recently in covering health disparities in the San Francisco Bay Area. He advised the audience to track public health money as it circulates from institution to its intended public targets. He urged newspaper and media research in order to gauge the deployment of resources to various communities.

A local medical journalist from Houston Public Television argued that race, class, and gender were more predictive of heath disparities than genetics. According to her, class disparities reflected resource disparities and this affected individual and family responses to health crises, particularly in terms of health insurance coverage and the medical access this provides. Using Houston as an example, she found that on average, the average household income in West Houston was $138K/year, with average expenses of $64K/year. However, in East Houston, the average household income was $24K/year, with expenses of $30K/year. This resource disparity frames the challenges facing low-income individuals and families' ability to secure ongoing health access, not only in terms of medical care, but also issues surrounding healthy food choices and environmental justice. The question posed at Mt. Olivet and echoed by Michaels remained urgent, "What are the emotional and resource burdens of care for individuals, families, and populations?"

The Phar Side of Diversity

I had never been so intimidated during my project research than when I sat in a large conference hall filled with researchers, graduate students, and community health workers of color facing a panel of pharmaceutical company executives and representatives gathered to address diversity issues both within pharmaceutical companies and in clinical research trials. Diversity on both the inside and outside of pharmaceutical production lay at the core of reducing health disparities, they came to argue. I was as unsure as to whether any of "them" were audio-visually recording "us" as they were unsure that any of "us" were recording "them." The panel chair made it clear that "This panel is not the panel to address questions of price, profit, and promotion. We ask that we limit our discussion to the topic of health disparities and the potential role of pharma in helping address them." Nerves were definitely on edge on both sides of the hall.

On that note, the session began with an African research executive for a large firm who said, "Big pharma is criticized a lot about what we do, with some people calling it 'the dark side.' Instead, I sought to bring diversity to research, finding most studies comprising 90 – 95% Caucasians. I argued that something was wrong with this picture." Citing the need for what she called "diversity science" her company now has over 200 research sites across the US and has identified and formed partnerships with an ethnically diverse group of physician-researchers. The company began its "diversity science" project by hiring ten African American and Latino researchers each, relying on them to raise issues of need in helping fine tune its research focus. As a result, the company then sought to hire 200 each of African American, Latino, Chinese, and White researchers.

> Recruiting was a learning experience – we were able to reach our hiring goals for Latinos, Chinese, and Whites, but were only able to recruit 67 African Americans. We need more African American researchers to reach out to the African American population. We

> are aware of the experiences of African Americans in medical history. But I am here to tell you that pharma is learning to listen.

I was not sure if what I had heard up to that point was tinged with humility, contrition, even a hint of confession. This tonality was maintained by the second speaker, a nervously awkward executive from another large pharmaceutical firm, who admitted,

> Pharma is a reflection of us, Whites. But our company, like the (rest of the) US, is realizing that we can't just focus on the majority population and those with power and money. We now have scientific basis for overseas trials – this is where genetics come in. We have to argue that different diseases originate in different ways in different people. We're here to spread the word so you can disperse it as a trickle-down effect. Biobanks – we need blood and tissue samples from around the world to understand how diseases manifest in different populations. The NIH has its own department of biobanking. This is a new way to look at diversity. The genetic diversity of populations, we believe, will drive medical advances in the near future. In ten years, people will wear a bracelet containing their genotype that can be used to risk predict, diagnose, and prescribe medications based on their genotypical signatures.

She then jumped from genotype to phenotype, claiming that drugs work differently in different racial groups. She said that her company was in the process of developing a race-based drug. However, a former research executive on the panel disputed claims about the efficacy of race specific drugs.
Offering the example of BiDil, a drug marketed toward African Americans,

> BiDil was not conceived as a race drug but apparently a population subset analysis claimed to show higher efficacy in African Americans. I was dubious, asked for evidence from the drug company and have never received a credible response. Nevertheless, the drug was approved. Today, no one talks about the efficacy of BiDil in African Americans.

She pragmatically outlined the role diversity plays in the corporate pharmaceutical and biotechnology mindsets;

> The population of the Unites States is becoming more diverse each year, with groups of people coming from areas of the world where drug companies are working in. Drug company research in those areas of world will not contract but expand. Companies are becoming increasingly aware of the need for this off-shore research in dealing with a changing US population of medical consumers. First and foremost though, pharmaceutical companies' main obligation is toward shareholders and profits. Orphan drugs

> are not profitable: Realistically, government and other public sector research groups should orient research towards solving diseases not profitable enough to warrant attention by big/private pharma.

The terseness of her statement indicated the limited degree of big pharma's commitment to bridging the valley of death in terms of improved health outcomes. There should be no doubt that ideas to income remain central to pharmaceutical company objectives. This in itself should bring no surprise. However her comment, along with that of those earlier in this section, threads together the envisioned role of diversity in pharma- and bio-technological research.

With the majority of the world's pharmaceutical profits are based on consumption in the United States, the increasing diversity of the US population rationalizes clinical trials in those countries and geographies of *origin*. Enlisting diversity within and without the company and within and without the country, it becomes possible to imagine the discursive, economic, and social circulations of power such engagements might set in motion. Race, ethnicity, national character, and market strategies all play a role in what one panelist remarked and the rest inferred, "Big pharma needs to reimagine its client base."

The next section examines the genetic research future promisingly tendered by the pharma panel. As we shall see, the enlistment of diversity requires the use of old categorical understandings of racial and ethnic difference, while problematizing their exact genetic definition and location.

Part Two: Genopolitics

> *"No idea is more provocative in controversies about technology and society than the notion that technical things have political qualities." (Winner 1986: 19)*

> *"Defining the molecular underpinnings of common chronic diseases has therefore become the central focus of genetic epidemiology. By extension, some investigators have turned with renewed enthusiasm to race as a tool for categorizing population risk. This approach draws on the practice, of long standing in the public health field in the United States, of granting priority to race or ethnic background as a demographic category — a surveillance practice, it is worth noting, that is virtually unique in the world."* (Cooper, Kaufman and Ward 2003: 1167)

I had landed in Raleigh-Durham. I was there to attend a meeting that brought together a cross-section of biological anthropologists, geneticists, molecular biologists, and epidemiologists whose work either directly or indirectly addressed the genetics of health in transnational and diasporic African descent populations. I had previously attended a health disparities symposium at the University of North Carolina, Chapel Hill. It was there that I met several African American genetics researchers and came to know more about how race plays into older notions of illness

risk within newer discourses about individualized genomic attributions of illness risk based on ancestry.

I entitle the second part of this chapter, "Genopolitics," for use not in the manner described by Fowler and Dawes (2008) who adopted the term to define the influence of genes on political behavior.[101] My aim is different. I wish to inversely deploy the term in analyzing the influence of biopolitics on the study of genetic behavior.

As a medical anthropologist, my preoccupative question going into the conference was, "How will genetic/genomic research (using new "technical things" to quote Winner) avoid discursively redefining race as biological?" By the end of the meeting, I had added another question of relevance, "How might the language of individualized genomic difference provide room for greater biopolitical surveillance and biomarket penetration of the citizen consumer subject?" Prompted by Cooper, Kaufman and Ward's influential and prescient 2003 piece in the New England Journal of Medicine, I will show in the following pages that while the former question arguably evoked a wide range of responses, the latter proved the topic of much conference debate. It appears that the technoscience of ancestry is as imprecise as the science of race.

In this section, I interrogate the coherence of genetic, genomic, and postgenomic explanations of the high prevalence of Type 2 diabetes and other cardiometabolic disorders among high-risk populations such as Native Americans, Latinos, and African Americans in the absence of an examination of the environmental, political, economic, and nutritional histories of these populations. To address this gap, I point out that longstanding, now naturalized notions of race and phenotypical difference attract investment into genetic research into diabetes amongst at risk populations. This approach could yield imperfect research results and contribute little to actually understanding diabetes. Yet as this research has suggested, some groups, particularly historically apprehensive and recalcitrant African Americans, remain the last frontier of inclusion into Type 2 diabetes programs, clinical trials, and larger biomedical projects. As such, these groups are biologically valuable, and as we have seen, much sought after by clinical and biotechnology researchers.

Therefore, race, I argue here, functions as a new form of biocurrency in the realms of biological, medical, and pharmaceutical research: While its economic value may originate in its political purchase, it does not translate into nor reflect the disparities in social capital amongst different segments of the population. Biological citizenship, in effect, reflects and inflects health disparities in both social capital and the existence of effectively dense social networks. However, locating and naming these biologies of belonging in racial terms is proving quite difficult for genomic science. This section illustrates that the science of locating *blackness* and naming *Africanicity* on the genomic map continues to spark intense debate among researchers.

(Con)Sequential Genealogies of Scale

As mentioned previously, the cost of sequencing a genome has fallen precipitously since the inauguration of this dissertation research project in 2008 (Drmanac et al. 2010). In his review of genome sequencing technologies, Metzker (2010) estimated that costs have dropped from $100,000 to $4,400 to sequence an entire human genome in the two years between 2008-2010. In 2011, The National Human Genome Research Institute (NHGRI) released data collected after tracking the costs of genomic analysis during the period from 2001-2011 (See Figure 1). Further,

[101] *See*: "Genopolitics". *NY Times* 12 December, 2008.

these new "second-generation" sequencing technologies perform greater coverage of a sequenced a genome by "re-sequencing" the genome up to thirty or forty times. This coverage sequencing (or "redundancy') permits reliably high-quality reading of a genome (Wetterstrand 2011).

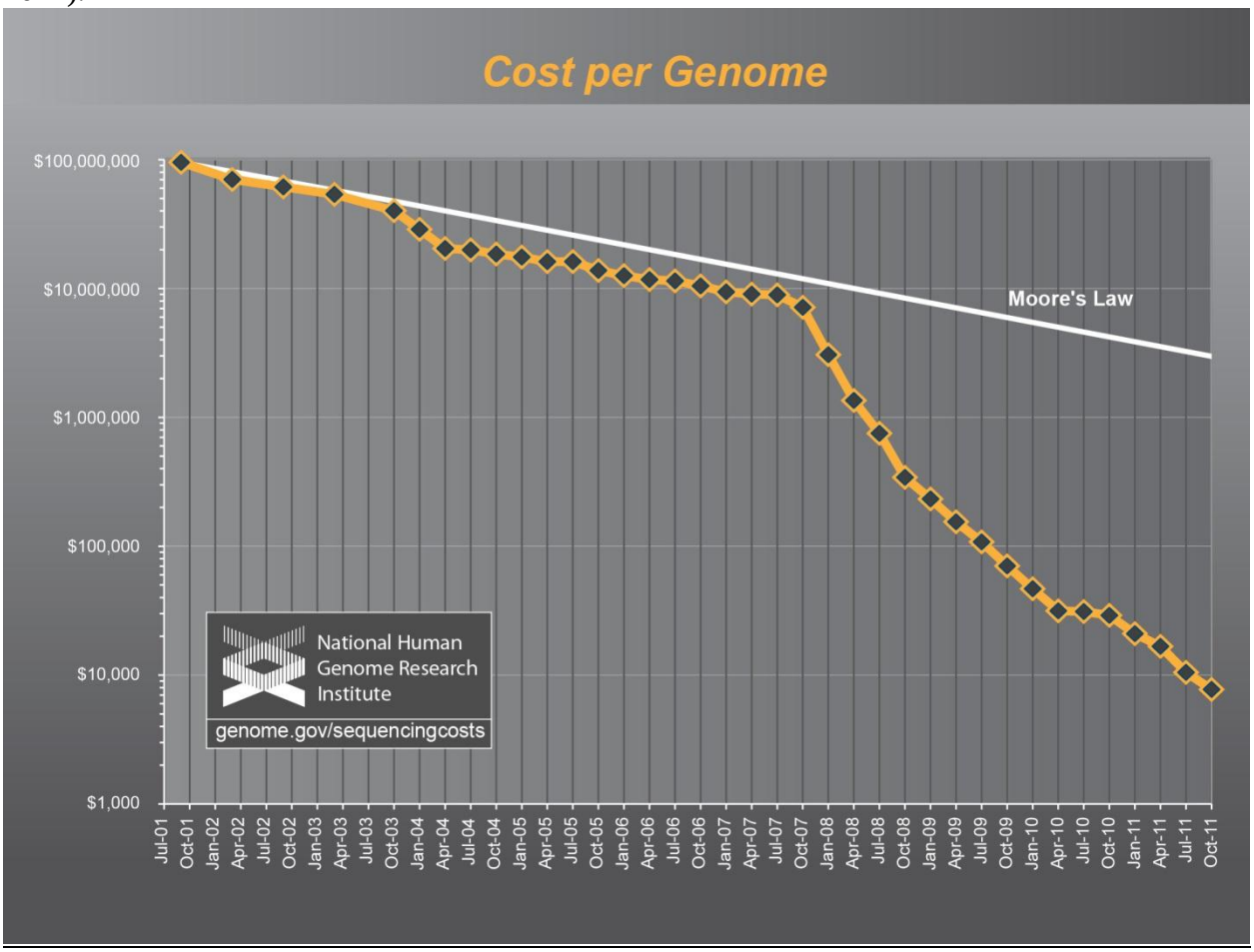


Figure 1. Cost decline in genomic sequencing since June 2001. Note sharp decline from July 2007 – October 2011. *Source*: National Human Genome Research Institute.[102]

A human genome consists of the twenty-three chromosomal pairs of DNA representing around twenty thousand genes. Whole genomic sequencing analyzes the entire genome, reading each of the twenty thousand individual genes, scripted in the form of letters, known as alleles. This whole genomic analysis searches for genetic mutations or variants that may signal disease risk. However, the twenty thousand genes packaged within the twenty-three DNA chromosomal pairs comprise ninety-nine percent of the genome. The remaining one percent of the genome contains a non-genetic material called an *exome*, which codes proteins within the genome. Some researchers see exomic research as the future of genetic investigations into disease causation, offering both greater cost-effectiveness and more useful data than whole genome sequencing (Ng, Buckingham, Li, et al 2009).

[102] Wetterstrand KA. DNA Sequencing Costs: Data from the NHGRI Large-Scale Genome Sequencing Program Available at: www.genome.gov/sequencingcosts. *Accessed* April 8, 2012.

The very second-generation technologies precipitating the decline in genomic sequencing costs make exomic sequencing possible. This decline in the cost of genomic sequencing outpaced Moore's Law, which posits decreasing costs over time due to technological advances that reliably result in a doubling of computing power every two years. "This facilitated the movement from genetics to genomics four or five years ago," said Dr. Mikel, a genetic/genomic researcher when we spoke in-between presentations. "We can now increase the number of genomes we put through analysis, producing millions of sequences in a single run." The economics of sequencing the human genome has, it appears, carved new research space for investigating both human and disease origins.

In the face of these technological developments, the National Institutes of Health (NIH) formed the Genome-Wide Association Studies (GWAS) in January 2008. GWAS was envisioned as a repository and database for the large amounts of genomic data emerging from sequencing technologies. A data sharing hub, GWAS aimed to foster greater coordination of research activities and outcomes.[103] The database, or dbGaP (the database of Genotype and Phenotype), contains data on unexpressed (genotypical) and expressed (phenotypical) traits found in different populations.[104]

However, in Chapel Hill, Dr. Mikel couched his excitement about new genomic analytical technologies with a dose of skepticism:

> Genomics cannot determine or predict disease risk, much less the height, of an individual, or for that matter, a group. Genetics cannot tell stories outside of history. We need more fully-sequenced genomes and exomes from populations with diverse demographic histories. We also need to fully map *past ancestry* before we can confidently predict *future risk* (my *emphasis*). At this point in time, we can talk about patterns and processes, but can say nothing at all about the people themselves.

Dr. Mikel's allusion to history proved interstitial to many of the presentations and conversations at the meeting. The political, economic, racial, bioethical histories of biomedical and biological research aimed toward African-descent populations in the Atlantic Rim and beyond, perennially re-emerged during these presentations and discussions. However, past historical social and health disparities elicited new concerns of future social and health disparities if African-descent populations are not enrolled in genomic research. According to the Genome-Wide Association Studies, 96% of genetic samples originate from those of Northern European background (*Ibid*). The meeting, therefore, brought to surface the uneasy balancing of the *necessity* of African-descent genomic research inclusion and participation in the generation of future knowledge, with the bioethics of such inclusion and participation.

Testing, Testing

The auditorium was abuzz during the morning question and answer session. An African American molecular biologist, visibly perturbed by the ways race had been linked to specific

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[103] *Genome-Wide Association Studies (GWAS).* US Department of Health and Human Services, National Institutes of Health. http://gwas.nih.gov/index.html. *Accessed*: April 16, 2012.

[104] *Genome-Wide Association Studies (GWAS).* US Department of Health and Human Services, National Institutes of Health. http://gwas.nih.gov/01faq2.html. *Accessed*: April 16, 2012.

genomic scripts in an earlier presentation, stated, "Ancestry tests for ancestors, not living people. It is an act of categorical misrecognition to attempt to explain genetic and genomic differences within human populations using the language of race."

There was a problem, actually two big problems – an epistemological one and an ontological one. The epistemological problem revolved around the definition of "African." The ontological problem, connected to the epistemic, surrounded personal identification in a "racial" or "ethnic" group. Both problems originate in the sociopolitical histories, geographies, and economies shaping such identities.

For example, another of that morning's presenters highlighted the problematics of identification in the face of both power and history.

> The population of the Dominican Republic has a heavy African component. In a continuum of *Africanicity*, from lowest to highest you have; Mexico, Ecuador, Colombia, Puerto Rico, and the Dominican Republic. Yet national and cultural narratives in the Dominican Republic focus on their 'European heritage.' Haitians are seen as the Africans although there are Dominicans with as much or more African genetic ancestry than Haitians. (*My emphasis*)

The molecular biologist's larger point sought to contest a definition of "African" as a member of a Sub-Saharan group on the continent. He argued that

> An African is someone who either originates from or lives within the African continent. It makes no difference whether what we call 'European' Y chromosomes are found in North Africa, the US, and South Africa, or 'Arab' Y chromosomes in the Sudan.

Dr. Scribner placed the blame squarely on 19th century biological anthropology and evolutionary theory, which equated an exaggerated Bantu phenotype as the prototypical "Negro." "This was about Europe and America writing an evolutionary narrative to themselves about themselves and those below them as a result of contact, colonization and slavery. Knowledge produced for domestic consumption and the exercise of power, but wholly inaccurate."

And therein lay another problem, one with historically social, biological, and now genetic interpretations. In social terms, scholars use words such as *hybridity*, *mixing*, *assimilation, creolization*, and the pejorative, *miscegenation*. In biological terms, the words *natural selection*, *cross-fertilization*, *genetic drift*, *founders' effect*, *biological diversity*, etc. come to mind. Sometimes, the biological and social terms find themselves used interchangeably, often quite crudely. Politically, *integration* and *multiculturalism* symbolize the historically interactive diversity of neoliberal democracy in the contemporary public sphere.

However, in population genetics and genomics, *admixture* redefines the above macro- and micro-analytical units of synthetic life using even smaller objects of observation at the sub-cellular level. The "act of categorical misrecognition" Dr. Scribner referred to repeated the conceptual mistakes of the past: the presumption that two or more "pure types 'mixed'," in the rather unnatural production of a new *sp. Homo sapiens sapiens*. The language of genetic admixture, therefore, carries with it the older baggage of racial categorization and social hierarchies of value. In a real sense, more scientifically precise in its inutility than

mulate/mulatresse, quadroon, octoroon, etc. served, and rather badly, in eighteenth and nineteenth century French Creole Louisiana.

For example, genomic admixture mapping seeks to uncover how genetic ancestry influences disease risk. However, it relies upon older classificatory language e.g. "European, "Native American," "African," "Asian," etc. in the search for the genetic defects/effects of these ancestries upon the health of admixed individuals and populations. Yet, some admixture mapping researchers recommend focusing on admixed African American and Latino populations due to their health status in the United States (Collins-Schramm, Phillips, Operario et al 2004, 2002). This despite the researchers' stated goal aimed to examine the effects of admixture, not *monorace*. Arguably, admixture inheres across all racial categories. Using this line of reasoning, genomic admixture mapping could, for example, uncover mutant or variant *European* genes implicated in disease risk for an individual or population classified as *African American* (Smith, Patterson, Lautenberger, et al 2004).
There was much debate, then, about *Africanicity* and *admixture*.

> It is extremely difficult to source (African) origins in an admixed population. And of course, there can be degrees of admixture even within the same population. The Southeastern United States has the least racially admixed and the Pacific Northwest the most racially admixed African American populations in the US. (So)Testing Afro-Caribbean and Afro-Brazilian populations can perhaps tell us more about African ancestry than United States African Americans – too much admixture.

Agreeing, another researcher offered a possible solution:

> The high percentage of Y chromosomes in the African American population makes mitochondrial (mt)DNA a better locus of study. It is a circular genome that is maternally derived. It performs no recombination, is traceable and more copies of it are available for study.

Dr. Barrington's comment favoring genomic studies focusing on African American maternal lines through mtDNA analysis coheres with the gendered social history in the US concerning interracial relationships. This line of reasoning, does not take into account those outliers with African American fathers' Y-chromosomes and White mothers' mtDNA from both in the shadowy private past and the more publically transparent present. However, Barrington's remark added a twist to understandings of heritability, the very issues of social and biological heritability which Dubois referred to in Dusk of Dawn.

Michael Montoya (2007) framed the term "bioethnic conscription," in seeking to define the ways the clinical research gaze viewed biological heritability through socially constructed racial categories.

> Rather, bioethnic conscription is a practice with at least two modes, one descriptive and the other attributive. In the first mode, ethnic and racial, hereafter referred to as ethnoracial

> classifications, are used to pragmatically describe human groups. They are used, for instance, to report to readers of scientific publications from which human groups the biological samples and data sets were derived for the study. The naming of human groups is a matter of method. In the latter mode, ethnoracial labels do more than identify groups: The labels are used to attribute qualities to groups. Attribution modifies, often in a delimiting way, what it refers to. (Montoya 2007: 95)

However, while *attribution* and *ascription* approach synomymity, particularly in regards to Montoya's description of scientific epistemology and practice, attribution does not convey the breadth of the total social field foregrounding such attitudes and practices. Further, as Montoya correctly argued, "Attribution modifies, often in a delimiting way, what it refers to." However, I suggest that *attribution* delimits social inequalities embedded within biological samples and data sets used in research. I use the social scientific term *ascription* rather than *attribution* to analytically engage the wider hierarchal social system of inequality informing research gleanings of both the biological sample and the data set. My argument rests on the assertion that ascribed social *inequality qualitatively* inheres to biological samples and the data sets, and precedes any quantitative analysis.

Although qualities can either be attributed or ascribed, only status can be ascribed. I base my approach on earlier anthropological work on ascribed status and the sociology of ascriptive inequality (Linton 1936, Davis 1950, Parsons 1970, 1951, Reskin 2005, 2003, Reskin and Branch-McBrier 2000). Therefore, while embracing the notion of "bioethnic conscription" as a descriptive form of scientific ethnoracial classification and attribution, I seek to analytically expand my inquiry to the wider social field. In the remainder of this section I aim to link estimations of racialized genomic risk with inherited status as a form of ascriptive inequality marking not only ethnorace, but also kinship, gender, class, and power.

Social and political scientific literatures have long framed African American, or by extension, Afro-Creole family structures as *matriarchal*, *matrilineal*, or *matrifocal* (Moynihan 1965, Frazier 1940, Smith 1956, 1988, 1996, Beckles 1999). Matriarchal and matrilineal designations, from an anthropological perspective prove quite incorrect and often misleading. Matriarchal societies pass on status and wealth to children through the maternal line but more importantly, figure prominently in the total political and economic structure of the group. Children in matrilineal groups inherit status and often, rights to resources through the maternal line. In a matrifocal society, children inherit neither status nor resources (or rights to them) from their mother. Within the context of US history, I would argue that matrifocality is the more precise term. Historically unacknowledged white paternity left, by default, the woman of color as the social focus and phenotypical locus of domestic reproductive difference and deviance. Therefore, matrifocality exists within larger structures and networks of patriarchal power and economic subordination. The One Drop Rule in the US resulted in children inheriting the racial status of the mother, a definition, following DuBois, rooted firmly in the economic desires of the day. I would argue that inheriting negative social status from the maternal line does not comply with the positive status and resource allocations enabled through either matriarchal or matrilineal social structures.

However, I submit that Dr. Barrington's (and others' present) argument for mtDNA genomic mapping of African maternal lineage, *would in practice*, redefine, *where applicable*,

matrifocality as Matrilineality: Matrilineality, in both the anthropological as well as the genetic sense of the word. In the biogenetic sense "Africa," as discussed, carries its own conceptual and interpretive problematics of locating Africa in the human genome. But in the former sense, the anthropological, matrifocality undergoes an apotheosis, acceding to a genetically validated matrilineality. However, having just defined matrifocality as bequeathing neither status nor resources, then what does one, or could one, or many, inherit from a genetically validated matrilineality?

What is inherited is disease risk, or to put it more neutrally, a genomic profile. Health status and Africanicity, reckoned through the genomic profile of the maternal line, offer new narratives of biological risk based on difference. However, the weakness of the paragraph's previous claim of a genomic accession of matrifocality to matrilineality omitted one important element defining matrilineality – the bequeathing of wealth and resources through the maternal line. While matrifocality (in a patriarchal system) bequeaths neither positive status nor wealth, then for the apotheosis and accession to be complete, I must explicate the source of this acquired (now inherited) positive status and wealth.

I suggest that positive status and wealth appear in two forms. First, positive status inheres to the scientific discursive validation and valorization of Africa as site of human origins and widest genetic diversity; and second, the wealth inhering to *Africanicity* in terms of biovalue to researchers. However, neither the scientific discourses validating and valorizing African origins, nor the biovalue of Africanicity carry over to the sociopolitical realm. As such, this accession in status and wealth is as ascribed as it is hidden, both genetically and economically (See Skloot 2010; Cf. Landecker 2007). I would submit this as a novel example of matrilineal counterpublics existing within larger patriarchal publics, one framework for examining the sociocultural construction of both a racial category and health disparities. These biosocial forms of wealth and status, I argue to be clear, are not acquired, but ascribed within hierarchal sets of socioeconomic relations. Significantly, although socially ascribed, this matrilineality is biologically inherited. Possession of both bio-wealth and bio-status exists elsewhere, primarily in the hands of researchers, institutions, and other biotechnological stakeholders. The bioethical and legal implications of these resource disparities and asymmetrical relationships are enormous.

Nonetheless, the ongoing narrative irony of risk seeks to recruit African American genetic donations under the banner of family, community, and justice.

Bioethical Conscription

"These are exciting times in genomic research, but with over ninety-five percent of all genetic samples coming from people of Northern European ancestry, we need to find ways of enrolling African American and other minority groups' participation in research," asserted an African American geneticist. For Dr. Ralston, this was a vital component of producing both knowledge and justice through "participation" by minorities, not only as research subjects, but as researchers. "If we don't care enough about what is happening in our own families and communities, then who will?" Ralston asked.

> If we aren't part of the planning, designing, and implementation of research on the genetics of health disparities, given the history of research on African Americans in this country, then how can we trust that ethics and accountability are not only built into the research, but actually happens in practice?

Dr. Ralston's rationale effectively calls for inducing a moral economy of African American genetic research participation, mobilized by a biopolitical racial category and its inductive sentiments. Rose (2007), Reardon (2005) and others have written of the efforts African-descent genetics researchers have made toward gathering more African-descent genetic material. Earlier concerns about African-descent exclusion in genetics research have given way to debates about bioethical inclusion given the proliferation of genetic material stored in biobanks and genetic information stored in databases, and the decreasing costs of genomic sequencing analysis (Mitchell and Waldby 2010, Greely 2009).

However, two meeting participants expressed concern about the bioethical ramifications of these new developments in genetic collection, storage, analysis and the social affect they may produce.

Dr. Mikel advised,

> The bioethics of enrolling more African American and other at-risk minority communities into genomic or pharmacogenetic research presents real challenges that must be faced. First, what would this mean for research participant or volunteer HIPAA (Health Insurance Portability and Accountability Act)[105] protection? Although HIPAA was designed to protect patient confidentiality, the government requires that for any university research, both the university and participant must sign over rights to the data collected. The data goes into a federal database. Once in the database it becomes publicly available and retrievable through the Freedom of Information Act. We must be sensitive to the potential that our data may in future cause the denial of health insurance to participants or stigmatize them in some way.

To which an attendee from Nigeria added, "We have problems recruiting people to take part in our breast cancer studies because their families are concerned that if they have the gene they won't be able to find husbands for their daughters." The subsequent silence to the statement brought home, to me at least, the diverse cultural histories and concerns framing the social fields in which genomics research occurs. I would also hazard that quite a few cosmopolitan ears were taken by surprise by Dr. Omowale's politically incorrect words of traditional patriarchal authority so uttered in a neoliberal democratic space. Dr. Mikel's comment centered, and quite appropriately, on the potential for added discrimination and stigma to a group with already low social capital in the US, yet where fateful outcomes tend to culturally bear upon the individual. Dr. Omowale's comment elucidated the potential for stigmatized alienation from the social group and diminution of marriage exchange value. Fears of genetic stigmatization could come to bear on the group as well as the individual, irrespective of class position or proximity to power. However, both Mikel and Omowale highlighted the ethical challenges to conducting genomic

[105] See: *The Health Insurance Portability and Accountability Act of 1996.* "The Office for Civil Rights enforces the HIPAA Privacy Rule, which protects the privacy of individually identifiable health information; the HIPAA Security Rule, which sets national standards for the security of electronic protected health information; and the confidentiality provisions of the Patient Safety Rule, which protect identifiable information being used to analyze patient safety events and improve patient safety." http://www.hhs.gov/ocr/privacy/. *Accessed*: April 13, 2010.

research, and even when ethically performed, the potential problematics of socializing the resultant data. Their comments brought to light two populations without adequate access to proper medical care, yet who are asked to participate in biogenetic medical research.

Granted, genetic research into disease risk and origin explores ancestral lines on a global scale, with an insistent recognition of human migration across space and time. However, my time in both the health disparities and genetics arenas, although based on the urgent premise of health inequality in African American communities left another concern: Whether ascribing disease risk in racial terms to groups with low social or evolutionary narrative capital could come to define, in practice, stigmatization itself.

I wish to offer an analogy here. I was reminded of a remark made by a Nigerian American health professional at a restaurant during the Houston health disparities conference. The television behind the bar was set to the Weather Channel and as it was mid-summer, the hurricane season was reaching its peak: "We have a huge disturbance forming in West Africa and as you can see, it is heading out over the open waters of the Atlantic. We'll keep an eye on it – it could potentially be a big problem down the road as it heads this way," the meteorologist valiantly declared. To this, exhibiting sarcasm touched with a healthy dose of incredulity, Ada wondered aloud, "Does anything good come out of Africa?"

I raise this analogy in suggesting that biogenetic information about disease risk among African descent populations (however biopolitically defined) may result not in improved health outcomes, but in fueling longstanding shadow narratives which perpetuate ascriptive inequality.

Genetic Ancestry, Type 2 Diabetes, and the Evidence

The exploration for genetic sites of Type 2 diabetes causation has until recently focused on small scale studies that uncovered only two loci, which when mutated, produced only a monogenetic (single gene) form of the illness, not the complex form commonly seen clinically. As related at the beginning of this chapter, recent advances in sequencing technology have permitted larger scale as well as meta-analytical studies. To date, these meta-analytical study outcomes have increased the number of potential loci discovered to forty-four. Although this seems promising, it represents only around ten percent of all the potential clusters of high risk families in Europe with Type 2 diabetes (Wheeler and Barroso 2011: 52).

Therefore the ninety-six percent of Genome Wide Association Studies (GWAS) samples originating in Northern European populations leave a wider phenotypical and genotypical research world of Type 2 diabetes risk to explore. The directionality of the genomic research gaze now eyes the wide genetic diversity of African-descent populations, along with South Asian and Native American populations in the hopes of making new genomic associations with Type 2 diabetes. As with the PreDX™ Diabetes Risk Score, the inclusion of African descent populations and others could help identify new "susceptibility loci," grow sample size, and improve power (*Ibid*: 57). So, in a very real sense, admixture is a problem. Africanicity is genomically where it's at.

Given the multitude of factors contributing to the development of Type 2 diabetes, such as obesity, physical inactivity, excess caloric intake, other approaches to the genetic study of the illness are being recommended. As mentioned previously in this dissertation, diabetics usually die from heart disease, kidney disease, stroke, with associated conditions such as hypercholesterolemia, hypertension, retinopathy, neuropathy and other circulatory disorders. Therefore, scientific arguments posit that researching the genetic causes of the Metabolic

Syndrome (MetS) in its entirety would prove more productive than a simple focus on the genetics of Type 2 diabetes alone (Tang, Hong, Province et al 2006).

The National Heart, Lung, and Blood Institute (NHLBI) Family Heart Study (2006) found genetic correlations to MetS biomarkers such as insulin resistance, waist circumference, hypertension, body mass index (BMI), HDL cholesterol, and triglycerides. However, the authors stopped short of attributing disease causation solely to genetic factors, concluding "These results suggest that pleiotropic effects of genes or shared family environment contribute to the familial clustering of MetS-related traits" (Tang, Hong, Province, et al 2006: 631). In other words, the researchers' ambiguous conclusion seemed unwilling to go beyond, much less settle, older now newer discourses of nature vs. nurture, genetics (DNA) vs. epigenetics (mRNA), genomics (mtDNA) vs. epigenomics (mtRNA) – or biology vs. culture.

One would think that genetic/genomic explanations of difference could serve to mediate confusion about race, ancestry, and disease. But how, when the only signifiers, or tools, for articulating difference remain embedded in older languages and assumptions about race? As we have shared, linking the genetics of race to the epidemiology of race poses another degree of explanatory difficulty.

In July 2000, Time published a cover story celebrating the work of Craig Venter and Francis Collins for successfully sequencing the human genome.[106] Heralded as a scientific breakthrough comparable to Watson and Crick's discovery of DNA, the mapping of the human genome portended a future both of greater therapeutic hope for some and for others, one of biological dread. It seemed as if the secrets of life had finally yielded to scientific investigation and that the tinkering was about to begin.

However, by 2009, a much more subdued optimism prevailed. "The publication of the highest-quality and best-annotated personal genome yet tells us much about sequencing technology, something about genetic ancestry, but still little of medical relevance" (Yngvadottir, MacArthur, Jin et al. 2009: 237). In 2010, Venter himself stated, "We have learned nothing from the human genome." He saw no short or medium-term applicability of genomic research to improving medical outcomes.[107]

In addition, recent research comparing a multi-ethnic Asian cohort with European populations found little difference in the genomic associations with two loci implicated in Type 2 susceptibility. Consisting of Chinese, Indian, and Malay samples, the study offered an opportunity to study ethnicities representing nearly half the world's population and much of the anticipated global growth in Type 2 diabetes. Although other genetic variants of possible interest were found, the study's authors suggested that European genetic data was potentially "relevant to Asian populations" (Sim, Ong, Suo, et al. 2011: 1-2). The variations found among and between the three Asian populations provided no clear ethnic population-specific associations with the two loci previously identified two loci found in Europeans. Interestingly, these less than enthusiastic findings echo Tethys BioSciences' own study which found no correlation between ethnicity and Type 2 diabetes risk.

Neither race nor genomics appear to offer clear guidance or instruction for improving medical outcomes. Nonetheless, or perhaps due to this, the genetic diversity of African-descent and comparatively othered populations are seen as biocurrency on the thoroughfare to future scientific discovery. However, at this time genetic and genomic investigation into declarations of

[106] See: "The Race is Over." *Time* July 3, 2000.
[107] See: "Spiegel Interview with Craig Venter" *Der Spiegel* July 29, 2010.

links between ancestry, ascribed race, and Type 2 diabetes remain both tenuous and premature. Genome-disease *associations* have yet to generate firm *correlations* that would confidently transform *susceptibility* into *risk*, and even further down the line, no *bio-assessment* of risk which would qualify for candidacy as an eventual diagnostic *biomarker*. Yet tantalizingly, the biovalue inhered to the genetic diversity of African-descent populations offer researchers many biological variables to explore.

Rebiologizing Race, Improving Surveillance?

Let us now return to my first question I carried entering the genetic field space, "How will genetic/genomic research (using new "technical things" to quote Winner) avoid discursively redefining race as biological? Having heard and seen both presentations and debates about racial and ancestral origins, their disputed genetic locations and disease causing differentials, I decided to raise the question. Dr. Barrington unequivocally answered, "It's not of question of when in a future sense. Race and the racialization of biology have continued unabated in present day genomic science." A molecular epidemiologist rolled his eyes upon hearing my question. "I think it is inevitable and unavoidable. I don't see any way around it even if I wanted to – and I do."

My questions followed on the heels of a presentation by a clinical researcher in medical practice who rather blithely deployed commonly used racial categories in his presentation. While commonly used racial categories are problematic enough, they become even more problematic, and more visibly so, when they contradict themselves. The presenter argued that African Americans have a low risk of developing osteoporosis and that therefore, popular medical advice recommending Vitamin D supplementation does not apply to that population. His evidence suggested that African Americans taking Vitamin D increased their risks of developing heart disease. And as usual, the White population served as the standard comparative measure. During the question and answer session, however, Dr. Michelin was asked, "From a genomic standpoint, which African Americans are you referring to? Africanicity and admixture complicate your claim. It doesn't mean that you're wrong – it just means that we get what our categories restrict and allow."

In response, *Dr. Michelin began* by maintaining that African Americans had bioprotectivity from osteoporosis and coronary artery disease (CAD) in the form of calcified atherosclerotic plaque but that "African-derived" risks extended to hepatitis C and kidney disease. *He went on* to add "I believe that the less than one percent genetic difference in human populations has massive effects on disease causation and protection." *However, Dr. Michelin concluded* by admitting "But to answer your question, my comments about osteoporosis and Vitamin D where based on phenotypical, not genotypical race data, all of it self-reported. So yes, I, most of us, could do a better job of more precisely defining the use of race in our work. But it's all we have."

Chapter Six: Translation and Outreach

> *". ...starting with the deliberately chosen example of the most artificial normalization, technological normalization, we can grasp an invariable characteristic of normality. Norms are relative to each other in a system, at least potentially. Their co-relativity within a social system tends to make this system an organization, that is, a unity in itself, if not by itself and for itself."*
>
> (Canguilhem: 1991[1966]: 249)

As I have attempted to show, Type 2 diabetes "norms" as well as "risks" share co-relativity within wider systems of sociocultural relations. This research took George Canguilhem's implicit suggestion of a potential phenomenological context in which the artificial can be rendered normal through a social system of organized technological practices. I stop short of locating the "deliberately chosen example of the most artificial normalization" in technology itself. I argue that the most artificial normality begins with the concept of biological race, not only as a measurable norm but also as a measurable risk. Genetic and genomic research cannot locate race as a bio-assessment; short of this, racial biomarkers for disease will remain elusive.

However, I found over the course of my research that race, as a most artificial normality, was also part of a social system of organized economic practices. In this social system of organized economic practices, race as epidemiological risk becomes mobilized in creating new forms of economic reward. Translating risk into reward presents yet another definition of the "Valley of Death," but not necessarily its solution.

My original interest lay in how these new technologically produced norms around diabetes and prediabetes were communicated through public health and biotechnological outreach efforts. I aimed to trace biotechnology efforts to reconfigure human practices in the hopes of forming new social systems of biological and market value. This dissertation explored how the development of one particular technology sought to conduct research among a social group it saw of biological and market importance.

Dr. Asela hoped that through public outreach in the way of diabetes education classes he might eventually attract African American patients. Yet, the mission of Rochester Clinical Research aims to enroll diabetes and other cardiometabolic patients in pharmaceutical trials. Tethys BioSciences hoped through public outreach to attract African Americans into its DRS research platform. The company thought valuable a socio-politically constructed racial category in the production of a risk-prediction tool of which race was not used as a biomarker. It sought to build race into the instrument itself.

The shift of evaluative Type 2 diabetes categorical gazes upon the body (such as race, ethnicity, phenotype, genotype, etc.) combined with the visual rationalities offered by HgA1C and blood glucometer technologies or the mathematical rationalities provided by the PreDx™ DRS algorithm—offer new interpretive schemata for Type 2 diabetes fact-making. As such, diabetes measurement technologies, whether diagnostic or predictive, arguably function as interpretive device technologies within changing temporal and biomedical classificatory schema and understandings. However, I submit that biomedical inclusion without social inclusion will remain a problematic and elusive goal (as long as an asymmetrical relationship exists between biological capital and social capital).

While the HgA1C test functions primarily as a diagnostic assessment, the patient relies on blood glucometer for daily monitoring of blood glucose levels. This monitoring informs and

is informed by dietary, pharmaceutical, lifestyle, and emotional (such as stress) elements affecting the patient's metabolic life. As such, the medical gaze upon the diabetic body cannot be confined to either domestic or clinical spheres, but must have mobility, portability, and reliability. This is essential in reflecting truth about the body back to the patient. Consequently, neither the family nor the clinician, as in past iterations of the medical gaze, occupies primary position of interpretation; the positional gaze has moved inversely to the patient himself, engaging with glucometer technology. The prompt to self-test, as evidenced by the barrage of ads for glucometers, as well as market, biotechnological, and pharmaceutical drives to establish prediabetes as a stand-alone disease category, heightened my inquiry.

However, the phenomenology, not to mention the ethnography of Type 2 diabetes presents two challenges. First, the Type 2 diabetic learns through experience and education that their subjective feelings are not to be trusted—only the glucometer readings reflect one's true physiological condition. This means that happiness could actually be due to high blood sugar, depression or moodiness to low blood sugar. Therefore, the patient must rely on the glucometer for a true indication of health and well-being. The second challenge is primarily ethnographic—how to chart the circulation of the artefact (whether blood, technology, or gene) and the newer meanings it promotes as well as the older histories it evokes.

Narrative descriptions of patients framing Type 2 diabetes causation as induced by precipitous events have been associated across and within ethnic, racial, and socioeconomic categories (Schoenberg et al. 2005, Cohen et al. 1994). The Alameda County Diabetes Project, a twenty-five year research study (1964-1999) found socioeconomic position (SEP) a greater predictor of Type 2 diabetes risk than either race or ethnicity. However, race and SEP are strongly correlated. Growing wealth disparities between high and low SEP groups portend an increase in the incidence of Type 2 diabetes (Maty et al. 2006:143). The concentration of Type 2 diabetes and prediabetics in at-risk populations may accentuate the frequency of these narratives of causation within these groups.

Merlene and I met for an early breakfast meeting one morning at a local Rochester restaurant. She recommended Unkle Moe's, a veritable institution in the *African American* community. Unkle Moe's doubles as a restaurant in the front of the property and a jazz and blues club in the rear. Given the importance of access to fresh fruits and vegetables, particularly in food deserts, Unkle Moe's is located across the street from the only remaining supermarket in Southwest Rochester's predominantly *African American* community. [108]

Over breakfast, our conversation drifted onto the topic of how people in the African American community view diabetes differently from the biomedical model and message – and how this affects her outreach work. Merlene firmly believed in biomedical and public health explanations of Type 2 diabetes as a biological inevitability depending on environmental, lifestyle, genetic, race, age, and/or dietary factors. This is the message she carries into the field. When I mentioned that there was qualitative research suggesting that minority patients tended to present narratives connecting precipitous life-events with a subsequent Type 2 diabetes diagnosis, Merlene commented

[108] When I was growing up in the Southwest Rochester, there were five supermarkets to choose from: IGA on Genesee Street; Star Market on Jefferson Avenue; two supermarkets side-by-side on West Ave. (across from Unkle Moe's); and an A&P Market at Bullshead Plaza, now the site of a police substation.

> My sister has Type 2 diabetes. She says the same thing and I always tell her that she's wrong. But you know she went through three really tough experiences one right after the other. A close friend died and then she went through a divorce. But that is not what the science says causes diabetes. The process, I believe, was already set in motion. I will keep this in mind, though, because it's not just my sister: I've heard this often in the past from other Type 2 diabetes patients.

Seen in this light, public health and the wider social service apparatuses must necessarily become adept at both envisioning and addressing the counterpublics existing within the interstices of the communities they imagine to serve. This effort could prove most difficult in addressing the needs of minority and youth populations that in many areas already exist under the surveillance of the criminal justice system and other forms of state discipline. Rendering these judicially marked bodies amenable to sociobiological investigation and regimes of technological surveillance and control requires profound understanding as to why some would be averse to such public health efforts, and perhaps rationally so.

The New York portion of the fieldwork reminds us of the ongoing irony surrounding the existence of health care disparities occurring most often in areas adjacent to medical universities and teaching hospitals (Smith 2005, Cf. Skloot 2010). Inclusion within political and epidemiological categories seems to guarantee little with respect to effective therapeutic inclusion. Just as the absence, *par terre*, of expertise in the form of endocrinologists and diabetes educators rationalizes the reliance on technological means of surveilling and managing Type 2 diabetes, exclusion as a form of contemporary spatial praxis, too, is tantalizingly open to (marketed) mediation through daily engagement with blood glucometer technology.

For example, throughout the three year research period I became acutely aware of the barrage of television and internet advertisements for free and discounted glucometers. As mentioned earlier, the economic benefit to device companies comes not from glucometer sales, but through the purchase of the testing strips required to conduct the test. At diabetes walks, free glucometers were given away to all and sundry, including this ethnographer, without regard to either Type 2 diabetes or prediabetic status, no questions asked. Medical inclusion, *gratis*.

Advertisements for blood glucometers overwhelmingly featured ethnic minorities, especially African Americans, as well as older individuals of all backgrounds. Type 2 diabetes, to reiterate, was formerly known as *adult-onset diabetes*; it primarily affects people over forty years of age. Although the current epidemic of obesity and sedentary living has begun to lengthen the age distribution of the illness, the risk for Type 2 diabetes generally increases as one gets older. Middle to older aged adults and at-risk minorities, therefore, tend to be well represented in both blood glucometer and diabetes pharmaceutical advertisements.

The market offers the promise of equal access and medical citizenship—via inclusion through participation in commodified networks that promise to deliver what the social will not or cannot. Making sense of the medical implies a multiplicity of flexible subjectivities and learning styles (Cf. Das and Das 2006). Through this lens the very nature and even existence of the social as an imagined public health target must be questioned in translating rational clinical science within irrationalized zones of human existence (cf. Biehl 2007).

Fueling these market and biosocial relationships is the political/economic tangibility of science as the rational organization of hope, which controls the levers of emotional resonance

affective of future senses of the possible, mediating action in the present. In this way, the body/mind encodes what society says is real (Delvecchio-Good 1990).

On Biological and Social Integrity

But after all of this encoding and translating, how does the organ speak? Can the organ speak? I submit here that different speech styles represent and elicit different hope styles. Diagnostic technologies claim to speak for what the organ can and cannot do, or rather, what has happened to the organ, the pancreas. Glucometers purport to speak for what the organ is doing or has recently done. Diabetes risk scores claim to speak for a pancreas that has not yet contemplated pathological action. Public health understandings and outreach efforts are based upon translated interpretations of a racialized pancreas indexed by risk. Pharmaceuticals claim that they can make the organ speak the true and authentic language of functional normalcy and rational efficiency. However, diet, exercise and lifestyle arguably articulate no claims beyond what not only the organ, but the entire cardiometabolic system itself conveys as a result of auto-mediation, of self-agency; which notably, is the only endogenous form of bodily mediation related within this paragraph. But can it be said that the pancreas, *a pancreas*, the pancreas of a Type 2 diabetes patient, has its own narrative of hope, a narrative of organic persistence which bespeaks its own integrity within a bodily constellation of systems, of life processes?

Betty Washington, the diabetes coordinator for the Alameda Department of Public Health, surmised,

> I sometimes wonder about what my pancreas has left, what it can do on its own. I take medication to control my blood sugar levels, exercise when I can, but in the back of my mind, I ask myself if it (the pancreas) can be made healthier, if there is something, an intelligence, that we're not paying attention to.

It is perhaps easier to hope for, to expect, therapeutic change and improvement through scientific advancement, rather than therapeutic change and improvement through social change. But the net effect of a scientific telos of hope in the absence of social advancement would be disparities both old and new, with new and old technological faces. I argue that violence is embedded within any teleological argument, the scientific narrative in this case of which the racial rationalization of health disparities is but one. The historical violence of racial science, as Charis Thompson (2006) argued, continues in the face of both natural and social scientific declarations that race as a biological construct has no basis in scientific fact.

I present this definition of violence by focusing on how social subjects as racial objects become embedded in new research ideologies of risk, how these ideologies are discursively framed and circulated by their authors and through which channels. This dissertation engaged the ways in which authorial attempts to evaluate, frame, and put into discursive circulation racialized interpellations of Type 2 diabetes risk were contested or taken for granted, with varying degrees of success. I suggest that inherent limits and intractable dissonances become produced in poorly translated attempts to explain how the body, the categorically defined body, is inhabited – and addressed (Briggs and Hallin 2007).

Moreover, this dissertation presented two case studies in which science, technology, and medicine emerged with new race-based motivations for scientific research and practice based upon racially differentiated disease profiles. An interactive relationship between biology and race

(Thompson 2006:547) exists dichotomously between researchers. Tethys BioSciences saw its attempts to test its PreDx™ Diabetes Risk Score and increase its market and clinical validity as predicated upon outreach to a population dense (yet strategically unknown) African American community. And not the least, overseas contract clinical research organizations facilitate clinical trials in the biotechnological hinterlands of phenotypical and bioethical otherness.

Urban Renewal programs in the early 1970s, the decentralization of Rochester to the suburbs, and the demise of the Eastman Kodak Company in the 1980s until the present, as well as gentrification in the 1990s and 2000s have left Dr. Asela searching for the key that will unlock the door to a hard to penetrate African American community. This while Mt. Olivet Baptist Church has taken as its charge the responsibility of community health outreach and service to those irrationalized "zones of social abandonment" (Biehl 2007) within "minoritized spaces" (Laguerre 1999), zones of human existence with their own rationalities, rationalities with a language Mt. Olivet understands quite well based on kinship, shared experiences and historical discourses about both the body, race, community, and biomedicine.

Reducing and eventually eliminating future health disparities becomes problematic in the face of a mass incarceration process that has collected millions of DNA samples from mainly low SES and minority populations. African Americans, Native Americans, Latinos, women, prisoners, and military personnel (among others) have accrued biological research value over the course of medical and biotechnological history. To be clear, I argue here for an ethnography and medical history spatially predicated not as much upon geographic distance, but social distance: Tuskegee was very much about the spatial and social isolation and concentration of its target research population. African American students conducting the sit-ins at Woolworth sought to break through the segregated barriers located in the limited public spaces afforded by the market. Rochester's Third and Seventh Wards served as the segregated residential geographic boundaries of the African American community.

The Tuskegee Syphilis Study reverberates through the minds of many in the African American community and informs both individual and collective group responses when exposed to the clinical gaze. While Tuskegee and Type 2 diabetes represent completely different illnesses with completely different causal factors, they do share one key element in common—the blood as locus and focus of pathology and therapy—in ways scientifically attributed to African Americans, Latinos, Native Americans, etc. The new political value of diversity drives new forms of inclusion in medical research that reconfigures both race and disease as biologically determined. Today, the research gaze focuses on the racial pathology of the gene, genome, and exome, redefining bioprospecting even further beyond, but including, the biome. Contemporary scientific research conducted and scientific knowledge gained based on notions of racial difference reflect the changing sociopolitical and now bioeconomic currency of diversity. While both biomedical research and public health deploy diversity in terms of data and message, respectively, they function at different levels.

Data and Message—Translation and Outreach

Translating biomedical data into a coherent public health message arguably confirms the structures and processes by which health disparities arise. What became apparent during fieldwork was the question of medical translation, or the communication of medical science to the public. Successful outreach efforts directed towards at-risk populations and communities depend in no small part upon cracking the translational code. However, *the public* comprise a

diverse group of patients, consumers, citizens, migrant farmworkers, and markets, oftentimes speaking different languages, with unequal access, voice, and visibility, not to mention interests.

During this research project, epidemiologist and public health professional articulations of the word *culture* were often invoked and employed (in the opinion of this anthropologist), in terms which the discipline used thirty or forty years ago. I heard *culture* deployed and defined in ways that reified culture as racialized and essentialized forms of social behavior. I would suggest a clearer picture would be obtained through a focus upon regional and community practices over time rather than upon race and culture. While mindful of the social valence of *race* and the politics of *culture*, neither term provides any specificity concerning what people in communities and regions are actually doing, and perhaps more importantly, what has been done to, for, and with these populations.

I have shown in this dissertation how I found patients, attendees at classes and workshops stratified more by race than socio-economic status. Diabetes education classes funded by private insurance coverage, conducted by public health workers among at risk populations, organized by churches as well as the private sector garnered different populations with different understandings of Type 2 diabetes. My research in these disparate venues evoked the incongruencies and asymmetries between racial capital and social capital and the ways in which they produce different possibilities and constraints. These forms of capital necessitated an excavation of how in both the medical literature and in scientific practice, longer-standing notions of race and the social have been applied to scientific research paradigms in ways which reproblematize kinship.

However, while I applaud these interventions by Mt. Olivet and other community based organizations, the spatial analysis here leaves me quite troubled. Informed by the case of the Havasupai, I am left wondering if the basis of Type 2 diabetes research ultimately is, to paraphrase, *about species adaptation to limiting environments*.[109,110]

What becomes racialized or ethnicized are notions of the inherent biology of certain groups based on the theoretical and scientific notions of the day.[111] Mid-twentieth century science misappropriated the thrifty gene hypothesis to incorrectly explain obesity in various Native American and Latino groups (Montoya et al. 2007, Fee 2006). These, along with the case of the Havasupai in Arizona, raise questions about the morality and ethics of these racial and ethnic correlations and associations about Type 2 diabetes causation and prevalence.

While I cast no political aspersions upon nor ascribe political motives toward what impels biomedical research and market viability vis á vis these various at risk minority groups, I will argue that the lack of sociocultural capital these groups possess, though different for each, is inverse to the amount of biovalue ascribed to them. I further argue that the spatial segregation

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[109] *Nature* 430: 500-502 (29 July 2004). In the 2010 case of misappropriated blood samples gathered from the Havasupai tribe by researchers from Arizona State University, 1990-1994, it was found that Havasupai genetic material was not used for the earlier research purposes intended and agreed to with the tribe as well as the Human Subjects/Internal Review Board at Arizona State University.

[110] *The Independent* (UK) (23 April 2010). Some of the collected blood samples were used for research into schizophrenia and the effects of inbreeding on the tribe. Ph.D. dissertations were written by and degrees awarded to individuals who based their work on the misappropriated genetic material; the material was even used by senior researchers as well. The Havasupai originally sought $75million in damages but eventually settled with the University for $700,000. The principle researcher, a *Drosophila*, or fruit-fly researcher and evolutionary biologist, listed her research focus as "species adaptation to harsh environments."

[111] See DuBois, 1940 *Dusk of Dawn*, and; Boas, 1945, *Race and Democratic Society.*

these unequal groups exist within serves the productive purposes of studying the biological mechanisms driving the development of not only Type 2 diabetes, but contemporary obesity and the entire cardiometabolic constellation of illnesses. It remains much easier and common for an at risk minority individual to receive *nutritional recommendations* than *meal invitations* from those who conduct the science, run the clinics, fund new biotechnologies, or engage in local philanthropy. Within these framings of race, space, value and inclusion live individuals with varying degrees of (medical) literacy, access, and notions of the body, all charged with the personal responsibility of rationally managing their diabetes and/or losing weight. This may require breaking with tradition and adopting the diet and lifestyle of the mainstream population by which the rest are measured, particularly the upper classes, especially celebrities.[112]

Of particular importance then, are the complex possibilities of fashioning a contemporary form of Type 2 diabetes subjective knowledge through ethical practice—namely, experience shaped through the ostensibly impartial, objective truth representations of blood glucose technologies. Through daily practice of technological self-monitoring, interpretation, and subsequent appropriate action, diverse discourses and assemblages becomes naturalized within the unitary entity of the subject, the device, and the pharmaceutical. Or, for that matter, between the subject and the risk score. This is not necessarily a question of method in qualitatively assessing therapeutic efficacy; however, it does provide a means of inquiring about how Type 2 diabetes subjects move from superficial acquaintance (*connaissance*) to embodied knowledge (*savoir*) about four things—the illness, its technological and pharmaceutical assemblages—and themselves.

Objective Self-Fashioning: Individualizing Pathological Kinship

Further, this section interrogates Type 2 diagnostic and risk prediction technologies as objects reflecting "truth" about the body back onto itself. Through historical scientific narratives about the blood, the cell, gene, and now the genome, racial and biological categories refract these truth claims about the body through shifting interpretations of both risk and relatedness. I problematize biomedical discourses about Type 2 diabetes through the familial, racial, and epidemiological categories they reconfigure in terms of risk and relatedness. I link these discourses of Type 2 diabetic risk and relatedness to the technological and pharmaceutical forms of compliance they rationalize.

Specifically, I center on the discursive venues within which these objectified bodily categories of kinship and risk organize, enroll, and produce new diabetic subjects and persons. This section also engages the category of the person, the glucometer, the genetic fragment, and the pharmaceutical as circulating artefacts. As circulating objects of contingent knowledge, I traced their discursive movement through clinical, public health, and patient/consumer venues.

Institutional relationships and marketing drivers, I argue here, reflect relatedness back onto the Type 2 diabetes patient through causal narratives of risk and inevitability. In effect, kinship—genetic, familial, racial, ethnic, and environmental—becomes the driver of both risk and emergent forms of bioliterary discipline. Thus, technological surveillance via glucometer technology and pharmaceutical compliance become part of lifetime treatment rationales designed to reduce the biosocial risks incurred by being related. I engage the positional shift from the clinician to the Type 2 diabetes patient as the new interlocutor and interpreter of these

[112] Social segregation and media integration, I argue, make celebrity bodies and practices more accessible than local bodies and practices.

technologically mediated truth claims—about the structure and function of the biological world — and the moral economy of what it means to be related. And what it means to hope utilizing a model of diabetes care based not on cure but control.

Within the variables of kinship (genetics), identity ("race," "ethnicity," "the nation"), and networking (degrees of medical citizenship), exists an individual patient-subject charged with the moral imperative of neutralizing both risk and danger through engagement with Type 2 diabetes technologies. *Control through discipline* is now the Type 2 diabetes subject's *raison d'être*. In other words, the morality to action must become the ethical practice of self-care, of self-government, of being truthful to one's self (Foucault).

One limitation to this study resided in the lack of Type 2 diabetics less than forty years of age encountered in the field. Granted, Type 2 diabetes is an illness which appears in geometrically larger numbers in middle-aged, less active populations. However, physical inactivity is no longer a middle-aged sport (and even that is historically recent). My concern lay not in locating those "hidden (pre)diabetics" of the hip-hop, rap, and swag generations to assist in facilitating their delivery to the biomedical research and clinical gazes, paradigms, and programs – far from it. My concern rests squarely on the issue of bioresilience, of how younger African Americans view the biological continuity of themselves and their communities, and just exactly how they define the body of community today.

This dissertation has endeavored to shed new light on Dumit's (2005) "technologies of representation" in exploring how new diabetes technologies reframe and black box notions of biology, society, and risk in producing new subjects and social spaces. Further, this project problematizes the role of technology in producing new medical/consumer subjects and citizens. Threaded throughout has been the tension between (early) Foucault and Haraway: between the surveyed, disciplined, and the controlled citizen; and the technologically enabled subject. While this tension is both theoretically and analytically important, it is not total, and most certainly not an intended dialectical relationship.

I wish here to engage Foucault's later notion of the care of self and technologies of the soul in order to think through the conditions of possibility for care of the self. What does this mean for the Type 2 diabetic, if as Foucault claimed "Truth ultimately cannot save the subject"? This interrogation provides a forum to help think through some of the larger questions my research evokes, and which most likely need further refinement and clarity. Specifically, what do these forms of contemporary daily monitoring of one's own blood have to say about Foucault's notion of care of the self? Moreover, as the diabetic is told to never rely on her own subjective feelings, that she must depend solely upon the gluconometrics provided by her device, is there any possibility here for a true regime of care of the self? As with Alcibiades in Plato's narrative, how does one recognize and account for a lack of pedagogical experience in organizing and implementing a new regime of caring for oneself within a milieu of incomplete (self)knowledge? How do these technologies inform, market, and enroll new subjectivities, such as the prediabetic, who is now technologically ascertainable, medically classified, and personally identifiable, yet remains symptom-free?

I question throughout my research how risk organizes and frames these public health and bioclinical questions and discourses. I examined how the cultural, epidemiological, and social attentive shifts from the event (or the disease) to the risk of the event occurring, contribute to enrollment of new actors in new roles under new labels of consumer, citizen, patient, subject. Type 2 diabetes is a disease that is quite amenable to positive changes in diet, exercise, and lifestyle. The ADVANCE, ACCORD, DPP, and VADT trials demonstrated the limits of

pharmaceutical blood glucose control methods in the absence of a comprehensive approach which addresses the overall cardiometabolic life of the patient. In the field, I was quite surprised at how often physicians, diabetes educators, and even medical device representatives explicitly stated this in numerous public forums and private conversations.

As we have seen, although blood glucose technologies of both diagnosis and risk precede as well as accompany pharmaceutical interventions into unchecked hyperglycemia, their role is far from a totalizing one. Individuals and organizations such as Physicians Committee for Responsible Medicine promote the possibility of reducing and eliminating one's Type 2 diabetes through diet modification. Patients interviewed during the course of this research admitted to using their glucometers sparingly, some depending solely on medication and clinical visits to the physician's office every three months for a Hemoglobin A1C test. "As long as my HgA1C stays under 7.0, I just walk every day and take my medication."

My fieldwork argues that Type 2 diabetes technologies may suggest rational biopharmaceutical interventions; however, patient subjectivity carries its own rationalities which cannot be predicted nor counted upon either by the market or the clinic. Of significance here is that what *remains* central to the unanticipated emergence of Type 2 diabetes subjectivities is the technology itself. However, the glucometer, OGTT, HgA1C Test, or for that matter, the DRS, can in the end, only serve as a call to action, to practice. Yet these prophylactic and therapeutic actions or practices do not always unfold in the biopolitical spaces of public health or the biomarket spaces of the biotech and pharmaceutical industries—nor are they always informed by them. Technologies of control are not necessarily controlling technologies.

For example, the T2 diabetic who chooses to follow the vegan diet advocated by Physicians Committee for Responsible Medicine, while perhaps doing much to lower his environmental impact, carbon footprint, and raise his HDL, may still utilize the blood glucometer daily, or; take the HgA1C Test every three months in the physician's office. Others using CAM (Complementary and Alternative Medicine) practices may rely on glucometer technology to assess the success of their biomedically contraindicated therapeutic efforts. It may be possible that these dietary and lifestyle changes were impelled by a high Diabetes Risk Score. But the primacy of risk as a notion by which contemporary life is organized, this research argues, will not diminish, nor will the role of technology as both object and practice in rationalizing subjective forms of agency around these risks.

However, from the patient perspective, this research questions public health and clinical attempts at inducing a moral economy, or better still a moral obligation to self-test, follow diet and lifestyle regimens based on the social facts of diabetes risk. Race and risk, as social facts, discursively, politically, and scientifically circulate, but do not necessarily morally constrain the individual to adhere to or comply with prescribed diabetes regimens, despite the cardiometabolic punishment, in a Durkheimian sense, that deviance guarantees.

Nevertheless, I argue that the consumer citizen, bioliterate in these social facts, is seen as a privatized manager of biological risk to public health and biomedical institutions, and a plethora of data points of biovalue to biotech and clinical research stakeholders. [113] Citizenship is a technology of different forms of government requiring different forms of discipline *in relation to others* (Hunt and White 2000). Racial and behavioral categories provide room for new explanations of risk, disease, and care to different populations in relation to each other. Therefore the consumer citizen patient, through relational obligations, labors in new ways. "Give me your

[113] *See*, Mitchell and Waldby (2010).

body and I will give you meaning, I will make you a name and word in my discourse" (de Certeau 1984: 149).

In the nineteenth and most of the twentieth centuries, care of the self as both social and medical practice existed relationally in terms of social and biological conformity, of the norm. Advances in genetic, genomic, and postgenomic research in the late twentieth and early twenty first centuries have facilitated the promise of a new personalized medicine based not on sociobiological conformity, but on genetic diversity and individual biological uniqueness. While this research has sought to show the disparity between diversity and racial capital, I suggest that both reinscribe kinship hierarchies through the new narratives they author.

Nevertheless, research continues apace exploring genomic causes of Type 2 diabetes as well as obesity – as well as genomic target drugs aimed at their treatment (or prophylaxis). Kinship in the form of genomic associations also calls into question epidemiological understandings of population health, as personalized medicine's future stakes depend on the development of economically attractive and technologically precise genomic and exomic assessments of individual disease risk. However, the pharmaceutical industry would also have to contend with an epistemic and methodological shift in focus from *demos* to *ego*. Pharmaceutical profitability has long been rooted in the development of blockbuster drugs and as a former biotechnology executive earlier in the dissertation stated, "Repeat users" (Cf. Dumit 2002). The generation of blockbuster drug profitability predicates itself on the epidemiology and biostatistics of population health epidemiology. That said pharmaceutical concerns will have to grapple with a promised personalized medicine rooted in individually determined genomic risk factors. This approach seeks to develop vaccines designed to bind to the risky gene. Vaccines, however, do not create repeat users. Herein lay the economic quandary. One alternative strategy would use genetic truth claims to target "the worried well," bringing an increased emphasis on the immeasurably subjectivity of "wellness" instead of the measurable objectivity (and accountability) of "health" (Rose 2007).

I have attempted an ethnographic history of the notion of diabetes, its contemporary public health framing, and the instruments and technologies employed in translating, reinterpreting and redefining the illness along collapsed temporal lines of clinical interpretation. This dissertation engages the shifting illness metaphors and signifiers Type 2 diabetes represents, the discourses of risk and control they generate, and the possibilities for a certain form of contemporary self-care—within the habitus of truth this particular Type 2 diabetes technological moment imparts. A concomitant rise in human inertia has been enabled by this epochal shift in technological engagement. This temporal shift in human praxis has witnessed its biological predicate in the increased prevalence in obesity and Type 2 diabetes. Technology not only enabled this shift: it measures, indexes, monitors, and surveys its movement in the digital effort to help us chart our individual and collective metabolic demise.

However, as dual ideological products of the market, both technology and Type 2 diabetes mutually contain the confounders of the various hegemonic risks they (re)present. In summary, I engage the contingencies and constraints inherent to these two marketed hegemonic forms (technology and Type 2 diabetes) in terms of the possibilities for a certain kind of life, a certain kind of freedom, a certain kind of knowing as a truth-seeking subject. In a very real sense, this dissertation offers a glimpse of a certain kind of subject who exists within the margins as a statistical outlier in the midst of discourses, metaphors, ironies, technologies, programs, and facts—a cultivator of certain kind of authenticity in an increasingly designed and engineered world.

Nevertheless, there is cultural inertia concerning the implementation of these new forms of prescribed Type 2 diabetes practices. The various historical urgings to care for ones' self highlight the very uncommonness of the practice of putting philosophy into practice, of transforming *connaissance*, or *acquaintance* into *savoir*, or *knowledge*, even amongst private and public health professionals charged with the pastoral care of the population.

An unclear, yet possible outcome of my research is that the contingent assemblages of self-care organized around these new technologically mediated understandings of the "self" may indeed prove useful for those individuals, or more accurately, those subjectivities, best aligned to reflexively transubstantiate their experiences and practices into a statistically unverifiable form of personal truth. In a real sense, this suggests ethnography of the statistical outlier as rule rather than exception (Cf. Adams et al. 2005).[114]

This dissertation is, in effect, an ethnographic dialogue between self and solution to an historically and technologically defined and interpreted problem—that of contemporary Type 2 diabetes risk—and the public health practices it rationalizes, the actors it categorizes and seeks to enroll, and the relationship between risk, prognosis, and speculation. It is within these intersections between risk, prognosis, and speculation where epistemic battles occur over what is "mere marketing" and what is "pure knowledge" (Greene 2007b: B12).

[114] For Adams et al., even the notion of "research" required a translational toolkit. Traditional Tibetan medical indices of therapeutic effectiveness do not tend to separate healing dynamics from social and/or religious processes. Medicine and disease are seen as caused by elemental imbalances, negative emotions, and cosmic energetics pervading creation in varying degrees depending on season, age, karmic debt, or astrological condition. Biomedical notions of therapeutic efficacy are predicated upon statistical determinations of risk generated from essentialized patient populations, rather than a focus upon the individual. It locates efficacy in the patient through the statistical mean, leaving no room for those statistical outliers representing real human, medical, and ethnographic "fact." In this regard, traditional Tibetan medical epistemology would assume these patient-outliers as examples of their system's rules, not exceptions (Adams et al. 2005:276-278). I attend the same concerned theoretical and methodological focus in arguing for ethnographic ontologies of the statistical outlier within the contemporary US Type 2 diabetic field.

Conclusion

The Industrial Revolution combined with the rise of science occurred during a historical moment. A moment which has facilitated the industrialization of scientific knowledge in ways that paradoxically coincided with the production of modern bodies set on a nutritional trajectory toward a future Type 2 diabetic epidemic and the creation of a Type 2 diabetes industry. In the West, the age of production has ushered in an age of consumption. Bodily practices forged by production have by and large been replaced by bodies slackened by consumption and technosocialized inertia.

New technological tools have appeared that measure the accomplished forms of metabolic affect this epochal shift from productive labor to consumptive labor heralds. My larger project places ethnographic and discursive analytic attention upon how these tools and techniques introduce and operationalize new pharmaceutical entrées within emerging articulations of Type 2 diabetes treatment rationales and imperatives. In the case of DRS technology, we've been given a truth claim by its authorial representatives concerning a new predictive form of technological veridiction. Without prejudging the content of this truth claim, I charted how this discourse traveled and was taken up by newly enrolled actors, institutions and stakeholders.

Further, I suggest attention to the culture of the rushed, over- and underworked, and stressed contemporary moment, one of socialized inertia embedded within harried lifestyles of misrecognition—which, for example, confuse *activity* with *exercise*. Of particular importance is whether this technosocialized inertia serves as a therapeutic confounder to the DRS and other potential future predictive Type 2 technologies, which so accurately chart the fluctuations in our pancreatic, individual, and collective corporeal integrity. If so, then the Type 2 therapeutic endgame may prove as elusive a goal through new early predictive technological intervention as with previous forms diagnostic confirmation.

However, genetic and genomic discourses of disease occurrence push the risk predictive authority of science even further back in time in ways which may make the DRS and even the glucometer obsolete. The amount of funding available for genetic and genomic research dwarfs whatever private capital Tethys BioSciences could ever reasonably hope to attract. Media, scientific, and other institutional actors constantly circulate conversations about genetics and genomics. These conversations saturate social life.

While it can be argued whether genetic and genomic discourses rebiologize notions of race, I will argue that these discourses inevitably rebiologize notions of difference. Given this discursive power, in ways possibly more persuasive than the DRS, genetic and genomic articulations of risk based on difference may indeed convey not the possibility of risk, but a confirmation of diagnosis. As a form of personalized medicine, genomic difference as individualized risk may come to supplant race as group risk. The development of genomic target drug vaccines to treat risk based on genomic difference could conceivably do away with the social inconvenience of current diet, lifestyle, and pharmaceutical approaches toward managing diabetes. Such a vaccine, so defined, would perhaps shift the language from that of diabetes management to one of diabetic prophylaxis. However promising new genetic and genomic research into disease causation and health disparities, no new biomarkers have yet emerged from these investigations. Narrative truth claims couched in the language of association, correlation, and causation may construct a model of Type 2 pathological gun, even a smoking gun, but has yet to explain the trigger mechanism which prompts such a gun to fire. A bio-assessment is not a biomarker, and a biomarker is not a disease. However, as with prediabetes and the moral

economy of the risk score, new technological instruments augur the new signs they read and interpret.

I question whether biogenetic risk as an estimable, predictive categorical construction of epidemiological inevitability can be neatly superimposed onto disparate social landscapes productive of both risk and inevitability. I doubt whether a disease caused by caloric excess, Type 2 diabetes, will one day prove a result of racialized group risk any more than was pellagra in the late 19th and early 20th century US, a disease caused by a deficiency of quality caloric intake. I concur with Sangaramoorthy (2008) that risk discourse, policy, and aversion are highly dependent upon class, educational attainment, and subjective positionalities within the fields of power of any given society (2008:202-203). I submit that these factors contribute as much to the occurrence of Type 2 diabetes as we know today contributed to the development of pellagra in the past.

I have pointed to the translational challenges facing biotechnological, clinical, and bench scientific research in effectively accessing and communicating Type 2 diabetes outreach efforts to at risk target populations. In effect, I argue that health disparities often begin at the top, based on incomplete knowledge of the cultural, economic, and social factors animating targeted population groups, as well as their historical construction, all of which inform their real health care needs. Expanding the ranks of certified diabetes educators (CDEs) to include community volunteers, professionals, and others with strong links to their own communities would do much to improve diabetes education outreach efforts. This would ensure that, for example, diabetes walks are not scheduled on Sunday mornings if one wishes to attract large numbers of African Americans—particularly when the institutional imagination envisions African American churches as indispensable to these efforts.

Further, Type 2 diabetes is an epidemiological, social, and economic phenomenon which, this research cannot help but avers, intricately demonstrates how use-cum-exchange values subordinate and subsume social relations. Emergent obesity, the technological and pharmaceutical penetration of the asymptomatic subject, and technological biosurveillance of the experiment (the patient) affectively excavate these subsumed social relations within ideological constructs shaping both the commodity and the biological sample. Public health prompts to get tested, media prompts to obtain free and discounted glucometers, and urgings of prediabetics to self-test (as members of a new illness category) raise important questions concerning how affect is produced through technological (self)inculcation through daily glucometer use. (Self)Experimentation restructures knowledges and further problematizes existence. The development of genetic testing kits for home use further complexifies epistemological and ontological knowledge structures and narratives of existence and belonging.[115]

I have attempted to help fill an ethnographic void by highlighting how scientists, clinicians, public health professionals, and venture capitalists reconfigure their practices to the specificities of changing subjects, objects, and milieux in contesting and reproducing the scientific auto-narrative of risk.[116] Therefore, this research has sought to address the ways in which diabetes has been recast as a technology of quantitative risk informing patient behavior and agency. Further, it illustrates the roles of industry, scientific and medical consumer stakeholder networks in redefining not only the illness, but also the very categories of *patient, consumer, and citizen*.

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[115] *See*: Bolnick, Fullwiley, Duster et al 2007

[116] *See*: Rabinow 1996

Technology has not only reconfigured Type 2 diabetes and the patient—it has also reconfigured the archive and the ethnographer. I cannot help but extend my interrogation of the metabolic present to the practice of knowledge production itself, particularly in terms of this dissertation. The physical requirements of fieldwork, while more or less consistently demanding, were not reflected in the shifts, some quite unanticipated, of conducting archival research over the three year course of this project. *The library as a physical structure*, of course, remained indispensable to this research, but *the text as a digitized entity* in the form of the .pdf file highlighted contemporary concerns about not only the future of the library, but also that of the newspaper and the book—in essence the future of publishing itself.

Over the course of this research, ease of access to .pdf files reminded me of the amount of legwork I had been "saved from" by not having to physically travel to several libraries and obtain sought after textual materials. In many respects, the paper chase has become the .pdf chase. This brought to mind the fact that technology, too, has had a hand in reducing the caloric demands of knowledge production within the bodies of contemporary knowledge producers, reflecting the very concerns and questions this dissertation poses surrounding the ways in which technologized forms of inertia become socially (and professionally) normalized and naturalized. The "context of people's lives" mentioned in Chapter Two describing the larger milieu comprising the contemporary social field found cultural resonance through the recursive process of ethnographic writing in the digital present.

Translating the Future

Camp Entrepreneur and the larger Center for Scientific Translation Institute at the University of California, San Francisco, along with Harvard, both seek to cultivate dual fluency in the market languages of science and culture by rerouting basic academic research toward venture capital funding networks and syndicates. The precarious economic climate at the end of the first and beginning of the second decades of the twenty-first century have made venture capitalists more risk averse and consequently less patient with five and seven year proposed research to market timelines. Yet, given the amount of money funneled into research over the last four decades, increasing pressure has been placed on biotechnological research in light of the disappointing record of generating improved health and financial outcomes in hollowing out the current research valley of death.

I have sought to critically situate this discussion and larger research agenda within a new Type 2 diabetes technological moment—the shift in the clinical gaze from *diagnostic* to *predictive* accuracy and from *illness*, to *risk*, respectively. Ultimately, this dissertation research questions whether public health outreach can successfully overcome the very corporate ideologies and technological rationales responsible for the sedentary construction of the contemporary Type 2 diabetic subject. Or, if such a possibility runs counter to the very ethos and interests of the market itself.

As related in Chapter Four, I received much enthusiastic support from African American Type 2 diabetes patients, health care professionals, and researchers who cited the need for more African American research expertise concerning the illness. While I was mildly surprised by the exhortations from the lay community, those from African American health care professionals came quite unexpectedly. What both groups implicitly suggested is the importance of African American participation in scientific knowledge production. As in the case of Tuskegee, "knowledge" produced by a high social capital group about a low social capital group should be seen and studied through the bioethical research lenses of the group over and under study.

Tuskegee, the DRS, and now genomic science hold out African-descent groups and comparative others as desirable population samples that will increase the power of instruments researchers hope will one day become tools. What remains unknown is whether these tools will help fashion future biosocial justice. However, the past and the present offer no sources of effusive optimism.

Therefore, I exit this dissertation project by calling attention to new asymmetrical power arrangements among and between both researchers and researched in formulating new narratives of human difference and disease risk. This African American STS, of course, must engage in critical "second-order observation" (Luhmann 1998) not only of the researchers themselves, but those in public health, clinical medicine, private practice, as well as in communities. The complicity of researchers and interlocutors of color dating back to Tuskegee rationalizes this approach. This would provide a more robust tracking of how the discursive circulation of power reconfigures the political economy of socioscientific difference-making and knowledge production.

Successful outreach efforts demand effective translation and explanation of the variables involved and the stakes concerned. However, as repeated in this dissertation through the examples of Tethys BioSciences and the Clinical Research Center, and as before in the cases of Tuskegee, Henrietta Lacks, and others, recruitment continues apace of a community of individuals without either equitable access to or resources for obtaining adequate health care. It continues on the promise of improved future health based on a telos of biomedical progress and social justice. Yet make no mistake, this is a biopolitics of the living and the dead, a dual *vivopolitics* and *necropolitics* of racial biovalue. The hematological focus of Tuskegee, the cytological focus represented by Henrietta Lack's HeLa Cell Line, and today, the genealogical focus of contemporary genomics emblematically thread together not only the historical demand for African American bodies in US scientific research, but also chronologizes different strategies of both overtly and covertly (as well as formally and informally) targeting outreach and translation to this imagined population. From a bioethical standpoint, *Africanicity* problematizes future strategies of outreach and translation toward Africa itself.

However, risk, and for that matter, science and technology, know no discrete racial, ethnic, national or state boundaries, no exclusive temporal or spatial domains. I contend that we must primarily attend to future sedentary environments of technosocialized metabolic affect in new (sub-) urbanities and ruralities, where new *corpi*, or bodies, of wealth, poverty, labor, production, consumption, classificatory politics, and disparity will take shape, *writ large*.

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