

# **Sweet Blood and Power: Making Diabetics Count**

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A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment  
of the requirements of the degree of Doctor of Philosophy in Anthropology.



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## High Sugar

Honey gave sweetness  
to Athens and Rome,  
and later, when splendour might rise nearer to home,

sweetness was still honey  
since, pious or lax,  
every cloister had its apiary  
for honey and wax.

But when kings and new doctrines  
drained those deep hives  
then millions of people  
were shipped from their lives

to grow the high sugar  
from which were refined  
frigates, perukes, human races  
and the liberal mind.

Les Murray. Included in *Learning Human*.

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# Abstracts

## ENGLISH VERSION

As recently as 1995, sweet blood did not resonate broadly as an urgent transnational concern. This thesis chronicles how diabetes mellitus, sweet blood, became recognized as a social problem besetting Canada, among many other countries.

This ethnographic study brings anthropological theories – developed for the most part to analyze the lives of “non-Western” peoples – to bear on “Western” philosophy, science, medicine, mass media, governments, and commerce. Throughout, this thesis challenges received wisdom about disease, technologies, kinship, commodification, embodiment, and personhood.

This thesis argues that a statistical concept, the population, is the linchpin of both politics and economics in large-scale societies. Statistically-fashioned populations, combined with the conviction that the future can be partially controlled, undergird the very definition of diabetes as a disease. In turn, biomedical knowledge about diabetes grounds the understanding of sweet blood as a social problem in need of better management. The political economy of sweet blood shows that, under “Western” eyes, persons can remain intact while their bodies – down to their very cells – divide and multiply, both literally and figuratively. As members of statistically-fashioned populations, human beings have a patent existence and many “statistical doubles.” These statistical *doppelgängers* help shape feelings, actions, identities, and even the length of human lives. They permit countless strangers and “lower” nonhuman beings – among them, mice, flies, and bacteria – to count as kin. Through the generation and use of statistics, people and their body parts undergo valuation and commodification, but are neither bought nor sold. The use of statistics to commodify human beings and body parts, this thesis finds, inevitably anchors biomedical practice, biomedical research, health policies, and the marketing of pharmaceuticals and all other things known to affect health.

## VERSION FRANÇAISE

Aussi récemment qu'en 1995, le diabète sucré n'avait pas la connotation d'une préoccupation d'ordre transnationale. Cette thèse raconte comment le diabète mellitus, le sang sucré, en est venu à être perçu comme un problème social affligeant plusieurs pays dont le Canada.

S'appuyant sur la théorie sociale et culturelle anthropologique – pour la plus grande partie historiquement développée dans le but de faciliter l'analyse de sociétés dites « non-occidentales » – cette étude ethnographique analyse les variantes « occidentales » d'institutions tels que la philosophie, la science, la médecine, les mass-media, les gouvernements et le commerce. Dans son ensemble, la thèse critique des idées reçues concernant la maladie, les technologies, la parenté, la transformation en marchandise (*commodification*), l'incorporation en habitus (*embodiment*), et l'identité (*personhood*).

Il est soutenu que le concept statistique de population est le pivot entre le politique et l'économique dans les sociétés « contemporaines ». Les populations organisées de manière statistique, combinées à la conviction que l'avenir peut être partiellement contrôlé, sous-tendent la définition même du diabète en tant que maladie. À son tour, la connaissance biomédicale à propos du diabète supporte la compréhension du sang sucré comme un problème social nécessitant une meilleure gestion. L'économie politique du sang sucré montre que, sous un regard « occidental », les personnes peuvent rester intactes alors que leur corps – réduits à leurs cellules – se divisent et se multiplient littéralement et figurativement. En tant que membres de populations organisées de manière statistique, les êtres humains ont une existence manifeste et plusieurs « doublons » statistiques. Ces sosies statistiques aident à moduler les sentiments, les actions, les identités et même la durée des vies humaines. Ils permettent d'innombrables étrangers et « sous » êtres humains tels que les souris, les mouches et les bactéries de compter en tant que parents. Avec la génération et l'usage de statistiques, les personnes et leur corps sont soumis à la valuation et transformés en marchandise mais ne sont

jamais achetés ni vendus. L'utilisation de statistiques dans le but de transformer en marchandise les être humains et les parties de leur corps ancre inévitablement la pratique et la recherche biomédicales, les politiques de santé et le marketing de produits et services pharmaceutiques ainsi que toutes autres choses reconnues comme affectant la santé.

# Acknowledgments

Many people and organizations enabled the composition of this thesis.

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Since 1990, when I was still an undergraduate, Allan Young has cultivated an interest in anthropological theory related to health, disease, illness, and thoughtful action. His lectures from over the years rang in my ears as I composed this text. It was a pleasure and a great help to discuss my findings with him, and his comments and overall support are greatly appreciated.

Ellen Corin encouraged epistemic analysis of public policies, medical diagnoses, and research, including my own ethnographic research. She prompted me to rethink what “reading” implies in a world that sweetens blood.

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While I was deciding where to pursue doctoral studies, Sheila Neysmith advised me to place a premium on the capacity of an institution to attract graduate students with similar interests. I have come to appreciate the wisdom of her counsel. Many current and former McGill graduate students (in anthropology, sociology, and history) supplied stimulating ideas and practical assistance that helped shape this thesis: Sean Brotherton, Dominique Behague, Janet Childerhose, Alicia Colson, Jennifer Cuffe, Ari Gandsman, Montasser Kamel, Yasir Khan, June Kitanaka, Mary Ellen Macdonald, Vinh-Kim Nguyen, Martha Poon, Janalyn Prest, Audra Simpson, Richard Scott, Samara Soghoian, Jason Szabo, Bob White, and Ann Yeh. During my tenure at McGill, I also met current and former Université de Montréal graduate students who aided and abetted my work: David Bernier, Kate Frolich, Maeve Haldane, Annie Lafontaine, Vincent Mirza, Lena Stan, and Alicia Sliwinski. Of the people named above, I am particularly indebted to Janalyn, who “talked through” the research process with me and who was the first reader for most of this manuscript; to Mary Ellen, whose doctoral research overlaps with this thesis, topically, spatially, and temporally; and to David, whose everyday life now entwines with mine, and whose superior computer skills furthered this project and averted untold disasters.

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June and George Rock, my parents, contributed to this project in countless ways. They instilled respect for learning, from books and through trial and error, and they equipped me with many of the capacities necessary to set a challenging course – and arrive.

# 1. Introduction

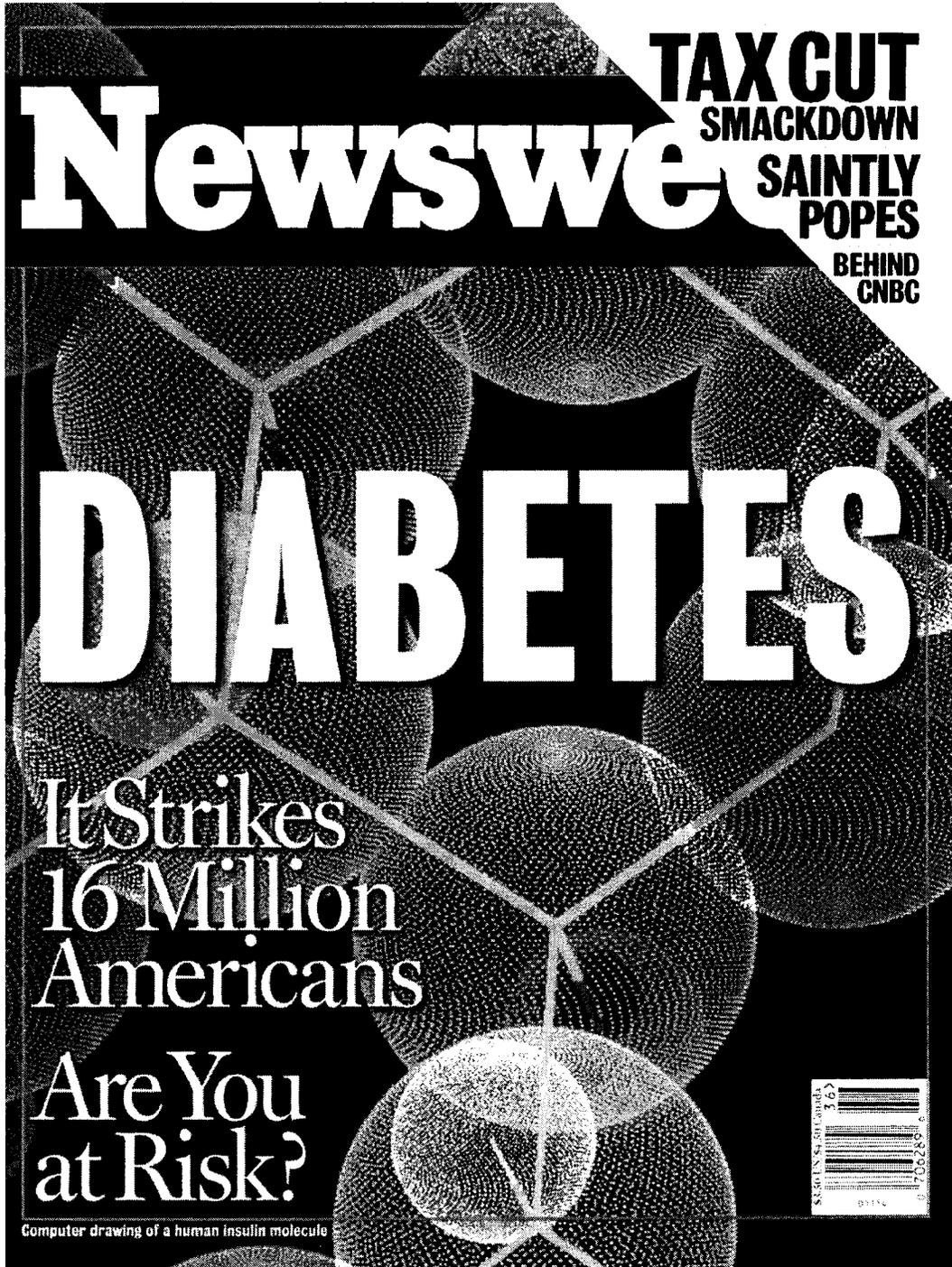
Something terrible was happening to Yolanda Benitez's eyes. They were being poisoned; the fragile capillaries of the retina attacked from within were leaking blood. The first symptoms were red lines, appearing vertically across her field of vision; the lines multiplied and merged into a haze that shut out light completely. 'Her blood vessels inside her eye were popping,' says her daughter, Jannette Roman, a Chicago college student. Benitez, who was in her late 40s when the problem began four years ago, was a cleaning woman, but she's had to stop working. After five surgeries, she has regained vision in one eye, but the other is completely useless. A few weeks ago, awakening one night in a hotel bedroom, she walked into a door, setting off a paroxysm of pain and nausea that hasn't let up yet. And what caused this catastrophe was nothing as exotic as pesticides or emerging viruses. What was poisoning Benitez was sugar. (Adler and Kalb 2000, 40)

Thus began the cover story of the 4 September 2000 edition of *Newsweek* (see Figure 1). After this gripping description of the onset of blindness and of the lingering footprint of a door in one woman's body, the reader learned that "Benitez is a representative victim of what many public health experts believe will be the next great lifestyle-disease epidemic to afflict the United States: diabetes." The authors hastened to qualify this assertion: "Technically, type 2 diabetes, which accounts for 90 to 95 percent of all cases." (Adler and Kalb 2000, 42)

In this day and age, sugar hardly seems exotic, nor life threatening. But familiarity has bred contempt, the *Newsweek* journalists took pains to impress upon readers. "Diabetes is a disorder of the very engine of life, a subtle calamity at the molecular level," the article explained. "Its hallmark is a failure to metabolize glucose, the ubiquitous sugar molecule carried by the bloodstream to

Figure 1:

Newsweek cover, September 2000



fuel every part of the body.” Glucose therefore accumulates in the bloodstream. “Deprived of their prime energy supply, muscle and nerve cells slow their function, which is why early diabetes may manifest itself as lethargy and irritability.” These and other “subtle signs” are “easy to overlook or deny.” (Adler and Kalb 2000, 43) The end result, in effect, is famine amidst feast. Without timely intervention, the cells that compose diabetic bodies can starve, even while the person gorges.

Yolanda Benitez was born and raised in Mexico, reported *Newsweek*, and at just over five feet tall and 140 pounds, she is considered overweight. She serves as a “representative victim” of diabetes in light of sweeping demographic shifts: “As the American population becomes increasingly nonwhite and obese, the disease is rapidly spreading.” (Adler and Kalb 2000, 42) Readers of this *Newsweek* cover story learned that “Hispanics and Blacks are more likely to contract diabetes than Caucasians,” while “American Indians...have the highest rates of type 2 in the world” (Adler and Kalb 2000, 42, 43).

*Newsweek* elected to run a cover story on diabetes in September 2000 because study released by the Centers for Disease Control and Prevention (CDC) found that diabetes is on the rise, especially type 2 diabetes. Diagnosed cases of diabetes increased by one third between 1990 and 1998, the CDC reported, from 4.9% to 6.5% of the population. Dr Frank Vinicor, director of the CDC’s diabetes division, termed the phenomenon a “persistent explosion” (cited in Adler and Kalb 2000, 42). Black, Hispanic, and obese members of the population accounted for much of the increased incidence of diabetes, but *Newsweek* underscored that “even among Caucasians – even among those of normal weight – the rates are on the rise.” In addition to the stunning increase in diagnosed cases of diabetes reported by the CDC, untold numbers live oblivious to the sweet blood coursing through their veins: “The actual number is almost surely higher, since many cases go undiagnosed for years.” (Adler and Kalb 2000, 42) “We’re living dangerously” and “Paying a high price” read the captions for the accompanying graphs and maps; total diabetes-related expenditures in the United States were estimated at

\$98-billion, compared with \$107-billion for all cancers (Adler and Kalb 2000, 42-43).

Breaking down the increased incidence by age yielded “the most alarming statistic.” Among Americans in their 40s, the incidence of diabetes increased by 40% between 1990 and 1998; among people in their 30s, the incidence of diabetes increased by a whopping 70%. Young adults and even children increasingly succumb to type 2 diabetes.

The growing incidence of type 2 diabetes among teenagers is “extraordinarily worrying,” commented Dr Arthur Rubenstein, an endocrinologist and dean of the Mount Sinai School of Medicine in New York City. “If people become diabetic at age 10 or 15 or 20,” he told *Newsweek*, and by extension, its readers, “you can predict that when they are 30 or 40, they could have terrible complications.” (cited in Adler and Kalb 2000, 42-43) The journalists rejoined, “You can also predict that they are going to need a lot of expensive health care.” (Adler and Kalb 2000, 43) In these regards, Yolanda Benitez’s daughter Jannette Roman is “an even more significant example” than her mother is. At only 18 years of age, *Newsweek* reported that Jannette Roman also has type 2 diabetes (Adler and Kalb 2000, 42).

The spread of type 2 diabetes down the age ladder has prompted a change in biomedical terminology, reported *Newsweek*. “In fact, until recently the disease Roman and her mother have was known as adult-onset diabetes, because it struck people middle-aged or older,” as opposed to “juvenile” diabetes, “now called type 1,” which tends to set in during childhood or adolescence (Adler and Kalb 2000, 42).

Yolanda Benitez, Jannette Roman, Arthur Rubenstein, Frank Vinicor, and the fact that I ever learned their names form part of an intricate nexus that stretches from Mexico to Chicago, the CDC headquarters in Atlanta to Canada, via the *Newsweek* editorial office in New York City, and beyond. By the time this edition of *Newsweek* materialized, I had been conducting field research for over a

year into the generation and dissemination of knowledge about diabetes, focusing on the situation in Canada.

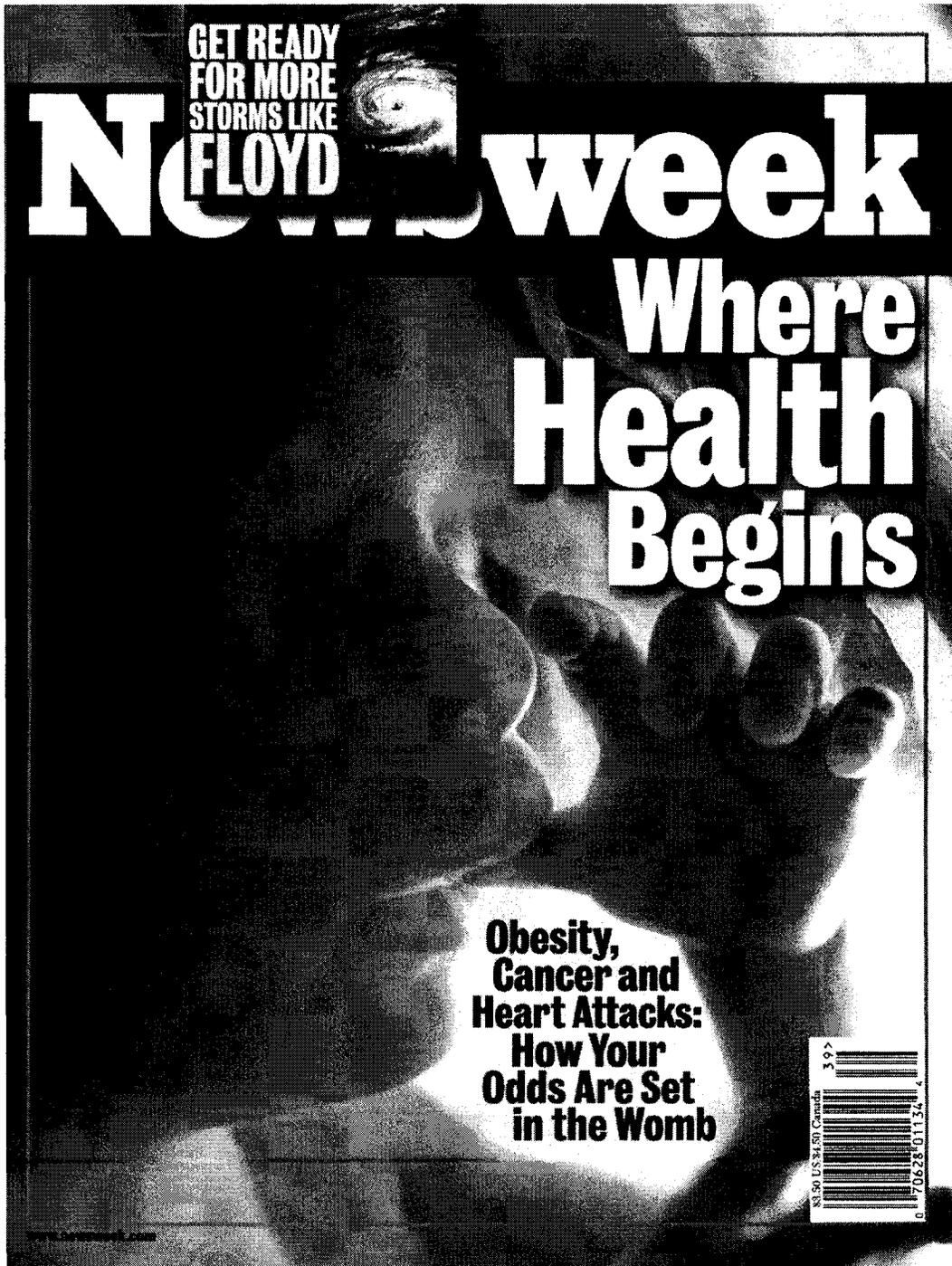
While Canada's demographic profile and health care system differ markedly from its neighbour's to the south, diabetes does not respect the border separating the two countries. Moreover, as illustrated by the broad circulation of *Newsweek* across Canada, knowledge about diabetes routinely flows across this boundary, usually from south to north. Indeed, prior to reading the 4 September 2000 feature article on diabetes in *Newsweek*, I had already encountered Frank Vinicor's name. His assertion that diabetes meets the three cardinal criteria for public health disorders – “a high disease burden, a changing burden suggesting preventability, and fear that things are unknown and out of control” (Vinicor 1994) – anchors the lead paragraph of the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* (see Meltzer et al. 1998).

Cognizant of my research topic, a confidant bought the 4 September 2000 *Newsweek* issue for me in a Canadian airport. When it came into my hands, I immediately recalled a *Newsweek* issue published almost a full year before, given to me by another confidant. The cover of 27 September 1999 issue displayed the title – “Where Health Begins” – over a photograph of a fetus (see Figure 2). The subtitle announced, “Obesity, Cancer and Heart Attacks: How your Odds are Set in the Womb.” The lead paragraph of that story profiled a 73-year-old man who has lived with type 2 diabetes and hypertension for at least twenty years, as he was diagnosed with these conditions in his early 50s. The editorial board did not consider diabetes sufficiently dramatic for the cover page, but diabetes figures prominently in the “typical case” mobilized to personify the lifelong impact of embryonic and fetal development. The diabetes cover story in the 4 September 2000 issue *Newsweek* vindicated my sense, shared by my informants, that diabetes was gaining recognition.

The treatment of diabetes in these *Newsweek* cover stories parallels coverage of the disease in three reports clipped from the *Globe and Mail*, a daily newspaper distributed across Canada to which I subscribe.

Figure 2:

*Newsweek* cover, September 1999



In 2000, a front-page article conveyed highlights of a Statistics Canada report in a manner that certainly encompassed diabetes, but without putting this disease in the spotlight (Leblanc 2000). The headline read, “Boomers suffer less arthritis, but more migraines.” The lead paragraph, however, indicated that members of this generation “stand a greater chance of having migraines, asthma *and* diabetes” (emphasis mine). A Statistics Canada spokesperson noted that better methods to detect diabetes and asthma might account for some of the apparent rise of these ailments, and that “U.S. studies have pinned the growth in diabetes on an increase in body weight and the adoption of a sedentary lifestyle.” In other words, this Canadian government official refers to studies such as the one that sparked *Newsweek* to introduce Yolanda Benitez as a “representative victim” of diabetes. Canada may be “doing better than the United States on a number of levels,” as this *Globe and Mail* story reported, but not on diabetes and diabetes data.

The headline of a *Globe and Mail* news item published the following year read, “Diabetes more prevalent than expected.” (Picard 2001a) This article reported that Drs Kue Young and Cameron Mustard estimate that about a third of all Canadians with diabetes remain undiagnosed. “This mass of invisible diabetics poses an important public-health problem because the undiagnosed tend to suffer from obesity, high blood pressure and high cholesterol – all risk factors for heart disease,” the *Globe and Mail* told readers. Undiagnosed diabetics “are also much bigger users of health-care resources” (Picard 2001a).

A few months later, on 24 July 2001, the *Globe and Mail* placed a story about type 2 diabetes on the front page. Entitled “Pudgy boomers face diabetes threat: Obesity rate has made ‘sweet sickness’ one of the fastest-growing health problems,” it ran as part of a series on Canada’s “growing fat problem.” The series was coordinated with CTV, a privately owned national television network and a sister company to the *Globe and Mail*. Like the *Newsweek* cover story on the rising incidence of type 2 diabetes, this article began by personifying the problem:

Dan Larlee's weight, like that of many men, crept up steadily over the years, and rose faster when he quit smoking. The combination of a busy professional career and raising a family left him with no time to exercise and little interest in dieting. Aside from having to get ever-larger pants, Mr. Larlee felt healthy and relatively fit.

But when he was 45, type 2 diabetes was diagnosed.

'It was pretty scary,' the Halifax accountant said.

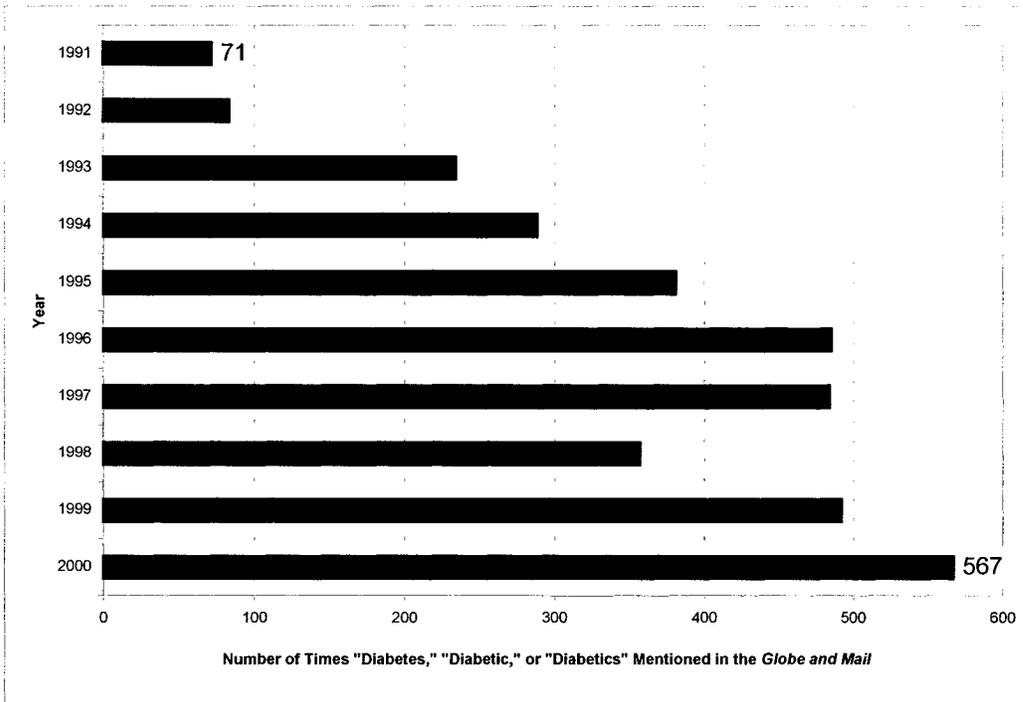
In a country where almost half the adults are overweight, many boomers will soon experience Mr. Larlee's fear firsthand.

(Picard 2001b)

"A seemingly mundane disease, diabetes is nonetheless the leading cause of blindness, amputation, and kidney failure, and one of the leading causes of heart disease," the article noted. "Diabetes already affects two million sufferers in Canada," the article continued. "Because of our collective pudginess, that number is expected to rise to three million within a decade." It also reported, "Diabetes is estimated to cost the Canadian economy about \$10-billion a year." Echoing the concerns voiced in *Newsweek* about the spread of type 2 diabetes down the age ladder, this *Globe and Mail* article ended by quoting Donna Lillie, national director of research and professional development for the Canadian Diabetes Association: "If we have all these children who have diabetes at 10, we're going to have a lot of people with heart disease at 30." (cited in Picard 2001b)

Statistical associations and projections propelled diabetes onto the front page of the *Globe and Mail*, just as the latest diabetes statistics from the CDC rendered this disease *Newsweek* cover material. Over the past decade, however, the *Globe and Mail's* coverage of diabetes increased eight-fold (see Figure 3). Donna Lillie, Kue Young, Cameron Mustard, Frank Vinicor, Arthur Rubenstein and other anointed experts have played midwife in the birth of a renewed understanding of sweet blood: as a noxious problem that is wreaking havoc in individual bodies and across populations

**Figure 3:**  
**Coverage of diabetes in the *Globe and Mail*,  
1991-2000**



In this thesis, I will examine in turn a number of the issues raised by the *Newsweek* and *Globe and Mail* articles captioned above: the hitherto invisibility of diabetes as a social problem; recent changes in the diagnostic criteria for diabetes; the tendency to rely on US data in estimating the total impact of diabetes in Canada; shifts in the epidemiology of diabetes; changes afoot in Canada to improve epidemiological and cost data related to diabetes; pride in Canada's health care system and high overall quality of life, especially in comparison with the United States; and how affected individuals, other members of the public, journalists, health professionals, corporations, and government officials perceive diabetes.

### **PROBLEMATIZING SWEET BLOOD**

This thesis presents an ethnographic exploration of the processes through which qualities detected in individual bodies may become construed as cause for public alarm. It highlights that raising public alarm involves understanding the problem in question as preventable or at least manageable, yet out of control. In the case of diabetes, "modernity" spells both progress and despair: progress because current treatments have been shown to slow the progression of diabetes; despair because available measures do not cure the disease and because modern-day "lifestyles" contribute to the problem.

The mechanisms and notions underlying the increased recognition of diabetes as a serious problem in Canada apply outside this territory. Diabetes has a higher profile in this country than it had ten, or even five years ago due to the circulation of knowledge generated in Canada, the United States, Britain, and other countries. The increased attention paid to diabetes hinges upon the valorization of the length and overall quality of human lives. Because the valorization of human life is not exclusive to diabetes, nor to biomedicine, "life expectancy" and "quality of life" could reasonably and effectively serve as fulcrum points to leverage interest in diabetes. The preference for a long, healthy life may seem obvious and universal, but this thesis underscores variability in the

ways and means through which value becomes vested in human beings. By documenting a shift over a short period of time in the status of a given disease, and, concomitantly, a particular human population, this thesis highlights how forms of expertise battened down the significance of diabetes, its “complications,” and associated “risk factors.”

I do not contend that Canadians, nor people in other countries, value life more today than they did five or ten years ago; rather, this thesis finds that diabetes became more closely associated with reduced “quality of life” and with “premature” death by 2000 than it was in 1990. Coupled with research findings, a broadly held preference for a long and healthy life led many people in Canada and elsewhere to recognize – to know again – what diabetes means for the bottom line, and for the persons in whose veins sweet blood runs. Previously, the “complications” from the disease were less amenable to prediction and control, and the diabetic population appeared to be smaller and stable in size. Moreover, diabetic “complications” routinely appear as separate illnesses in statistics, effacing their link to sweet blood.

Crucially, through the application of biomedical expertise, the amount of sugar in a modicum of blood indexes the present and future value of life for whole populations, and for the individuals who make them up. In evaluating the present and predicting the future, preferences and morals become compressed in numbers: invariably statistics, often dollars. The expression of the length and quality of human lives in numerical values has greatly contributed to the association between diabetes and “health risks.” In recent years, figures indicating that diabetes worsens lives and that diabetes is on the rise have proliferated. Through the generation and circulation of numbers testifying to the deleterious effects of sweet blood, a variety of actors have framed diabetes as a problem in need of redress.

Documentation of the impact of diabetes explicitly valorizes human life as sacred, but the process also involves evaluating the worth of life available to different people. To “valorize” raises or fixes the value of something, typically a

commodity, by such artificial means as government intervention, according to the *Oxford English Dictionary*; “valuation,” meanwhile, involves estimating the worth of something, and applies mainly to professional appraisal. These definitions suggest that assigning a value to something always requires human handiwork. Ironically, taken together, these definitions also imply that expert appraisal does not “artificially” determine worth. In the case at hand, the valued “thing” in question is a long, healthy life, while the “artificial means” that affix value encompass statistical expertise.

Within a society so large in scale as contemporary Canada, the definition of social problems requires ready statistical descriptions, such that people simultaneously embody physicality, categories, and numbers (Hacking 1986). In this thesis, I examine how biomedical research employing statistics can ground recognition of social problems, that is, common conditions or behaviour regarded as undesirable (after Blumer 1971). Media outlets have been fingered as key institutions in the recognition and very definition of social problems (Bernier 1999, for example). As illustrated by the *Newsweek* and *Globe and Mail* articles that dealt with diabetes, captioned above, journalists – not to mention social scientists – typically and selectively draw upon “expert opinion” to classify social problems and to attest to their gravity (see also Woolgar and Pawluch 1985). Lobbyists and government officials also routinely enroll health professionals and scientific findings to lend credence to their cause.

Throughout this thesis, I usually refer to “sweet blood,” rather than to “hyperglycemia,” to “diabetes,” or to “diabetes mellitus.” The less technical term, “sweet blood,” reflects how people diagnosed with diabetes often refer to their condition. English-speaking diabetics, for example, routinely talk about “my sugars” when discussing the management of the disease and its visceral impact on them. The sweeter the blood, the more danger a person is in, according to recent biomedical research. While remaining faithful to current biomedical knowledge about diabetes, the term “sweet blood” also raises the question of why, exactly, this condition is understood to be hazardous. In other words, this study views the

association of danger with “sweet blood” as a human accomplishment, not as an inevitable, “natural” occurrence. Put another way, it behooves the anthropologist of biomedicine to signal that the definition of diabetes, or any other disease, does not stand outside history and culture.

The term “sweet blood” also reflects a key finding of this thesis, namely, that the diagnosis of diabetes involves the reckoning of kinship, a perennial subject of study for anthropologists. Biomedical knowledge about sweet blood traces affinities between utter strangers and even between human beings and “lower” organisms, while also routinely cementing kinship between immediate biological relatives. The reckoning of kinship across large groups who lived and died in past, who exist in the present, and who will inhabit the future underpins the recognition of sweet blood as a social problem. The definition of social problems, not only sweet blood, routinely involves defining the members of large populations as akin to one another. The fact that the diagnosis of diabetes pivots on a quality exhibited by blood, however, neatly highlights that kinship is at issue since in English and several other European languages, blood is a common metonym for kinship.

## **POINTS OF DEPARTURE**

This thesis stands at the confluence of anthropological approaches to understanding the embodiment of knowledge, economy, and politics. It presents an analysis of liberalism and capitalism that expressly includes biology, from genes found in nonhuman organisms, to the projected membership of the human diabetic population in the year 2010 and beyond.

### ***The Embodiment of Liberalism***

As liberalism took root in Western Europe, especially during the eighteenth and nineteenth century, it distinguished itself as a political philosophy by delimiting the legitimate exercise of power by political authorities. “Society” came to signify a realm of freedoms and activities marked by certain tendencies. Liberalism assimilates the recognized needs and the known machinations of the

physical human body into “the nature of things,” while cultivating particular forms of embodied subjectivity.

Liberalism, like all (political) epistemologies, entails an account of its subjects. Liberal subjects are individual human beings; they come equipped with inalienable rights and discrete bodies; they can know, learn, discern, feel, communicate, and act (cf. Rose and Miller 1992, 179). Individual liberal subjects ideally exercise sovereignty, at will, over their lives through the medium of their physical bodies. Liberalism valorizes those subjects deemed capable of bearing a regulated form of freedom. “Private” and “public” operate as watchwords, marking the embodied will and rightful prerogatives of liberal subjects, singularly and collectively.

According to liberalism, governments ought to serve subjects by stepping in to further the public good, principally by preventing, mitigating, or punishing excesses. Of course, definitions of “excess” and “the public good” must be defined, and are therefore subject to negotiation, contest, and debate. The state owes its authority – its legitimacy – under liberalism to the notion that it can express the aggregate will of its subjects, particularly through periodic “fair and free” elections. Governance, therefore, is *not* exclusive to governments, according to liberal tenets.

Liberalism holds that governance largely and rightly takes place at a remove from state structures, but, for better or worse, states may coordinate, marshal, and leverage the capacities of citizens and all other available resources. “Liberal” governments represent but one class of institution through which subjects may manage themselves, fellow subjects, and “nature.” In positing the existence of an autonomous realm in which human societies “naturally” develop, liberalism vests the capacity to shape circumstance in individual minds and in sanctioned institutions, but also in hard-and-fast physical materials.

Since liberalism took root in Western Europe over 200 years ago, it has co-existed with, and even underpinned explanations for, numerous other forms of governance. The presumption that social scientists can account for how people

(other than themselves) live and think owes much to the liberal understanding of human subjects as sharing an essence that may take myriad forms. Given the historic emphasis in anthropology on “stateless” societies, the broad liberal conception of governance has been particularly important in conceiving “culture,” “politics,” and “economics” as a perennial but highly variable features of human history.

Social scientists tend to presume abstract subjects in analyzing actual liberal governance, which sublimely expresses the liberal ideal of mastery. Notwithstanding a recent trend towards elucidating how people participate in their own governance, social scientists frequently portray “liberal subjects” as functional extensions of the powers that be. Yet liberalism holds that all forms of governance will – and should – remain incomplete. Under liberalism, the key question is how best to marshal the available resources in service of set goals, from the proverbial halls of power to the more modest realms of clinics, kitchens, and drugstores. But by construing politics as a “mentality of rule,” and by focusing on projects deemed complete by state bodies, recent theoretical engagements with liberalism have inadvertently smoothed over “the intractability of what it seeks to govern” (O'Malley, Weir, and Shearing 1997, 502). These theorists are courting the danger of replacing dethroned monarchs with a medusa figure, spewing state-sanctioned experts who lord over a passive populace.

While this literature clearly and explicitly draws inspiration from Michel Foucault's concept of “governmentality,” close inspection of his influential essay on the subject reveals that Foucault understood historically-contingent “mentalities” to be entwined with, but not strictly determined by, physical materials (see Foucault 1991 {1978}). In fact, the material manifestations of thoughtful action figure prominently because they ultimately accrete to help shape varieties of subjectivity. Moreover, historical analyses of human societies ultimately follow and interpret such material traces. The present thesis examines how and why, under the auspices of liberalism, the vagaries of human bodies can pose social problems. It resuscitates Foucault's original insights about the

material dimensions of liberal governance, finding that the rise in concern about sweet blood embodies the obstructed quest for health and happiness.

A spate of publications published during the 1990s claimed that “neoliberalism” had supplanted plain old liberalism (see Clarke 2000 for a pithy review). These publications detect a renewed emphasis on entrepreneurship and on institutions other than the state in securing health and happiness. Several authors have, indeed, proclaimed the demise of “the” welfare state. In the proclamation of the primacy of neoliberalism, many analysts have implied that a few nation-states (particularly England and the United States) represent the vanguard, even the epitome, of global trends. Having rejected the notion of universal “stages” of development, anthropologists who discern “neoliberalism” when afield may implicitly hew, once again, to a vision of history as a march in lock step – if not towards progress. Paradoxically, by describing the contemporary period as riven by neoliberalism, as compared with a welfare ethos, analysts may cultivate nostalgia for the not so distant (and in its time, thoroughly critiqued) past. Meanwhile, many programs that marked “the” welfare state remain – however changed or strained – in Canada and many other countries.

Liberalism, with its emphasis on inalienable rights and modifiable capabilities, is supremely flexible. Untold permutations of this epistemology have already existed; yet more still seem destined to come into being; all merit fine-grained, ethnographic scrutiny. Ethnographic research can suggest how, and how much, global trends such as “neoliberalism” and “welfareism” find expression in specific locales. Ethnographers have shown that the “back to basics” shift associated with the neoliberal epithet has entrenched inequality in new guises, both “at home” and “abroad” (Farmer 1997; Susser 1997, for example).

Several “partnerships” between governmental and non-governmental agencies, as well as between individuals and institutions, feature in this thesis. Some, but not all, of these initiatives could be described as “neoliberal” or as “welfarist.” For the sake of simplicity, I use the terms “liberal” and “liberalism” throughout. For the sake of ethnographic integrity, I document *how* they pose the

problem of sweet blood. In doing so, capitalism becomes grist for my analysis. Liberalism and capitalism, this thesis finds, criss-cross through flesh and blood.

### *The Embodiment of Capitalism*

“The modern history of capital dates from the creation in the 16<sup>th</sup> century of a world-embracing commerce and a world-embracing market.” (Marx 1954 {1887}, 145) Capitalism hinges upon private property, which owners may convert into cash or otherwise deploy as they see fit, subject to the imposition of rules and to the inculcation of norms. Due to this inherent flexibility, many capitalist formations are highly compatible with the tenets of liberalism. Slavery, which played an integral role in the development of capitalism, is not. During the Industrial Revolution in the nineteenth-century Europe, periods of time lived in human bodies – as opposed to human beings outright – became a common commodity. The human capacity to labour was bought, sold, and harnessed alongside with other things. Together with dramatic technical changes, such as the invention of new machinery, the mass institution of wage labour enabled the mass production of standard items.

During the 1990s, just as welfare states reportedly mutated into serial “neoliberal” instances of entrepreneurship, anthropologists discerned an increasing variety worldwide in capitalist forms (Blim 2000). In the history of the discipline, by contrast, commodities mass-produced under capitalism were often viewed as so many Trojan Horses, sure to overpower local particularities with their monotonous yet convenient homogeneity (Miller 1995). But human beings have created manifold ways of interpreting and employing, “consuming,” such things.

Faced with myriad capitalist forms, how might anthropologists and other social scientists identify what they all have in common? How does capitalism, in all its variety, diverge from every other pattern of thoughtful action? It has been suggested that capitalism “consists of the organization and utilization of labor and effort for profit – the bare minimum of a definition to which all are likely to

agree” (Blim 2000, 33). This thesis focuses on how bodies and other materials participate in politics and economics, and not only through waged labour, so I find it helpful to recast slightly the definition above: all capitalist formations organize and utilize human bodily capacities alongside other resources for profit.

This understanding of capitalism, following Marx, presupposes that money is the measure of profit. Money can convert into manifold advantages or benefits in various capitalist formations, both directly (through trade) and indirectly. Money existed in “the West” long before the rise of capitalism, and something akin to “Western” money was indigenous to many other societies. But as capitalism intensified and spread, money gained purchase across vast expanses, and people increasingly projected the value of money into the future. For example, the invention of life insurance presupposed that a fixed amount of money could secure the “style of life” of beneficiaries following the death of the persons insured (see Daston 1988). Capitalism differs from other systems in the extent to which money serves as a standard measure of value, but (varying) limits on what money can buy still obtain in all capitalist formations.

### ***Stating Facts, Through Thick and Thin***

By examining how social relationships and technologies traverse the past, the present, and the future through the medium of living bodies, this thesis contests the notion that the market integrates the economy, while the state encapsulates politics. Instead, this thesis fastens upon a statistical concept, “the population,” as the linchpin of both “politics” and “economics” in large-scale societies. Population statistics and their many uses constitute cultural feats, demonstrably located in time and space. Discursive and inscribed references permit populations composed of human beings, or dollars, or other things to multiply, divide, and meld. Money “in the bank” (but actually lent out) and “people with diabetes” index fixed material entities, to which spoken words and printed numbers may refer. As “social facts,” members of populations have both an authentic existence and manifold *doppelgängers*; their “social lives” largely

unfold at remove from their origins, but are no less genuine for representing, rather than behaving. Because statistical technologies filtrate many domains, including public programs and private enterprise, biomedical categories and the populations that they define may obtain broad application and significance. Virtuality matters, helping to shape the conceptualization and even the material composition of the physical body.

Until recently, social theorists dismissed statistics as arid and banal, despite the enormous impact of statistics on human lives and thinking. In the latter decades of the twentieth century, the historical and social significance of statistics attracted the attention of several scholars, among them Michel Foucault (see, in particular, Foucault 1978 {1976}; Foucault 1994 {1978}).

Marshalling Foucault's insights about the importance of statistics for the institution of new forms of knowing and governing, research has highlighted the significance of statistically-conceived populations for colonial rule beyond Europe, as well as for the rise of liberal democracy and biomedicine in Europe (Appadurai 1996; Desrosières 2000 {1993}; Hacking 1990; Porter 1995, for example).

Leaning on the anthropological insights of Jack Goody and the philosophical insights of Foucault, among others, Bruno Latour underscores the importance of squiggly lines and pieces of paper – “inscriptions” – for knowing and governing on a global scale, inclusive of ideas and practices marked as “scientific” (Latour 1990).

Benedict Anderson nods to Foucault, but he relies primarily on a rich array of historical sources along with diverse social theorists – among them the philosopher Walter Benjamin and the anthropologist Victor Turner – to excavate the importance for nationalist feeling of such measures as standard timekeeping, maps drawn to scale, and census classifications (Anderson 1991 {1983}).

The burgeoning specialty of medical anthropology owes much to Foucault's reading of “Western” history (Young 1982; Lock 1993a), which foregrounds the importance of statistically-defined populations. To date, however,

the population concept has retained a rather low profile in this field. More often than not, medical anthropologists treat “populations” as unremarkable social facts, although they routinely deem demographic and epidemiological statistics “thin,” in need of the thickening that only ethnographic description can provide (Kleinman 1995b; Trostle and Sommerfeld 1996). Few ethnographers of biomedicine have analyzed the generation of statistics, nor their deployment (but see Farmer 1992; Frankenberg 1993; Gifford 1986; Kaufert and O’Neil 1993; Lock 1993b; Rapp 1995; Young 1995).

The contemporary world over, biomedical and other practices that affect well-being routinely unfurl along statistically-justified lines, if not always according to stated objectives. Nevertheless, in addition to bracketing the status of statistics as cultural objects, anthropologists who analyze medical systems have rarely investigated the fabrication and rending of “policy,” that is, the principles and courses of action sanctioned by governments and other institutional bodies (after Boulding 1967). Only recently, anthropologists “discovered” policy, noting that policies intertwine with health and social status, and raising questions about the appropriate role for the discipline in developing policy and in evaluating its effects (Shore and Wright 1997; Okongwu and Mencher 2000). The discovery of policy as suitable for anthropological exegesis, and discussions about the proper place of the anthropologist in making and breaking policy, builds upon critiques published from the 1970s through the 1990s of European colonialism and of anthropology’s role in it (Pels 1997 for review).

At this juncture, “the government” regularly supplies the steady state of “context” in the writings of (medical) anthropologists, as opposed to the lively content supplied by the everyday lives of the citizenry. Social historians have foregrounded biography and *bricolage* in shaping “the” welfare state (see Kelm 1998; Struthers 1983 for Canadian examples that speak to the broad, variegated impact of colonialism). Ethnographic projects, by contrast, have tended to consign to the backstage the volunteers, activists, bureaucrats, lobbyists, expert witnesses, politicians, judges, and members of their entourage who have a hand in designing,

evaluating, and justifying policies (but see Abélès 2000; Herzfield 1992; Povinelli 1993).

From the outset in this project, I was interested in how biomedical statistics feature in governance, but I did not anticipate that my research would entail revisiting social theory about the exchange of people and things. During the course of fieldwork, a variety of practices backed by statistics prompted provocative questions that interlace with exchange theory. When vials routinely substitute for a body's own insulin, or a dialysis machine compensates for a kidney that has ceased to function, how do such relations of dependence mitigate against emotional and physical detachment often thought to characterize commodity exchange? When a health condition is understood to be treatable and even preventable, and thus it may seem possible to exchange a diseased body for a healthier one, to what extent have individuals and populations undergone commodification? This thesis deals with such questions head-on.

The present work may be read as an extension of two landmark monographs in anthropology: *Sweetness and Power: The Place of Sugar in Modern History* (Mintz 1985) and *Culture and Practical Reason* (Sahlins 1976). Marshall Sahlins sought to dismantle the idea that in "the West," people think and act parsimoniously, guided by self-evident interests. Sidney Mintz, meanwhile, investigated how global trends in production and consumption help structure the composition of human bodies, in and beyond "the West." Both Mintz and Sahlins espouse and expound an anthropology steeped in political economy.

Contributors to the political economy tradition share a concern with the generation and allocation of surplus in a given (geographically-delimited and historically-contingent) system. In the political economy tradition, "surplus" does not refer to what is left over after meeting needs, but to things removed from the control of the people who made them. By contrast, neoclassical economists focus on the cumulative, localized effects over time of individual choice under conditions of scarcity (Gregory 1982, 6-7). Whereas the political economy tradition understands the principles that organize "the economy" to differ by

society, the neoclassical tradition regards individual decision-making as a stable, consistent, overarching process oriented towards the fulfillment of “basic” – read “biological” – needs, followed by wants. According to the neoclassical model, the natural and built environment introduces variation in production and consumption by prefiguring individual choice.

In the political economy vein, variation in the classification of some things – but not others – as suitable for giving, taking, trading, or frittering away has fascinated many anthropologists. They have also studied the various ways in which “non-Western” societies have assimilated “Western” goods by way of locally-salient values and practices. Mintz (1985), by contrast, examined how a “Western” society orchestrated the mass production of sugar in “non-Western” locales, and the unforeseen effects of mass absorption of this product within “the West.” Sahlins, meanwhile, has laboured to expose the cultural eccentricity of supposing that “individual rational choice” and “scarcity,” upon which neoclassical economics pivots, exist in the first place. In *Culture and Practical Reason* (1976), he underscored again and again that people make meaning out of their lives. Classification helps generate and affix meaning – to the point that the practice of distinguishing “wants” from “needs,” as well as “rational” from “irrational” actions, permeates Western philosophy and everyday life. Sahlins’ treatment of meaning as a kind of “product” recasts “surplus value” in the political economy tradition. Symbols may be apprehended in and derived from human bodies, but symbolism cannot be eliminated from human beings. Sahlins argues that political economists must take into account how meaning threads through human action, through the give and take of society.

This thesis builds upon the contributions of Sahlins and Mintz to political economy in ways informed by studies of embodiment, biomedicine, science, and exchange published since the mid-1980s. These diverse sources share a concern with how human abilities and proclivities shape – and are shaped by – the generation and transmission of knowledge. They also share a renewed appreciation of materiality as integral to human societies. Wedding the

Foucauldian concern with quantification and other forms of expertise to “surplus value” in the political economy tradition, the present ethnographic study extends theory about “biology,” “economics,” “politics,” and “culture.”

### *Sweetness, Power, and the Visitation of Disease*

Mintz places a manufactured form of sugar, sucrose, at the centre of his examination of the the political economy of the English diet from the 1500s into the 1900s (Mintz 1985, 5), while this thesis hinges upon glucose – the kind of sugar that human bodies derive from sucrose and all other members of the carbohydrate family.

The present study picks up from Mintz’s description of shifts in the composition of human populations – their thoughts, feelings, locations, and actions as well as their very physicality – that accompanied and abetted European colonial expansion, the entrenchment of capitalism, and the rise of liberalism. Transformation, albeit of different orders, obtained as much in “the center” as in “the periphery,” he shows. Mintz chronicles the conditions through which English capitalists came to profit from the derivation of massive amounts of sucrose from cane grown in the Caribbean, using the labour of slaves shipped in from Africa and land expropriated from a decimated indigenous population. The ships that brought slaves from Africa usually carried sugar, sucrose, on the journey back to England. With the passage of time, English and then American populations were re-made, quite literally, into different sorts of people, with distinct roles and preferences and needs and worries, as “sugar pumped into every crevice of their diet” (Mintz 1985, 188). Indeed, Mintz points out, the Industrial Revolution was fueled by sucrose as well as by coal and steam. “By no later than 1800, sugar had become a necessity – albeit a costly and rare one – in the diet of every English person; by 1900, it was supplying nearly one-fifth of the calories in the English diet.” (Mintz 1985, 6).

During the 1900s, the average proportion of sucrose in the “industrialized” diet did not exceed one-fifth of total caloric intake, but the average number of

calories consumed ballooned. Meanwhile, average caloric consumption also increased in “less developed” countries. Many of the additional calories came from carbohydrates, including sucrose. Due to increased consumption, the global amount of glucose circulating within human bodies increased dramatically in the twentieth century.

“The first sweetened cup of hot tea to be drunk by an English worker was a significant historical event, because it prefigured the transformation of an entire society, a total remaking of its economic and social basis,” Mintz concludes, before charging anthropology with a renewed mission: “We must struggle to understand fully the consequences of that and kindred events, for upon them was erected an entirely different conception of the relationship between producers and consumers, of the meaning of work, of the definition of self, of the nature of things.” (Mintz 1985, 220) The present thesis accepts this challenge. In particular, it treats the measurement of the sweetness of blood as a “kindred event” to the proverbial nineteenth-century English factory worker sipping a blend of two fruits of colonialism, tea and sugar. This thesis focuses on the generation and circulation of knowledge in the 1990s about the many human beings known to harbour excess glucose at work, rest, and play. More specifically, I examine how the sweetness of blood currently titrates the amount, quality, and cost of life in store for human beings. Thus, this thesis places biological knowledge squarely within the realm of political economy.

This thesis does not dispute the veracity of contemporary biomedical knowledge about sweet blood, but it regards the production and consumption of biomedical truths first and foremost as social facts, as things that particular people have fashioned, used, transformed, and discarded. By contrast, the project that Mintz defined for himself treats the human body as a discoverable yet malleable given (see, for example, Mintz 1985, 179). For Mintz, political economy encompasses the contours and the inner reaches of human bodies; but for the most part, he does not regard the production and utilization of knowledge about sweetness in human bodies as part and parcel of political economy. With respect

to human biology, Mintz provides a reading of history that suggests the triumph of reason but not utter progress. He questions theories proposed in the past about the benefits of sugar consumption for human beings, and he notes that contradictions between modern biomedical advice and modern ways of life burden individuals, both with health risks and with inhibitions about eating. The statistical reckoning of “life chances” currently takes sugar consumption into account, such that individuals regularly reach informed “personal decisions” in environments that preach moderation but promote the consumption of sweetened foods (Mintz 1985, 212).

Capacity – power – emerges in this thesis in ways that partially mirror the account by Mintz. “Few concepts in the social sciences have caused as many disagreements as the concept of power, and no satisfactory consensus on its definition has emerged,” understates Mintz. “But there is no way to avoid the term – or one like it – when the objective is to clarify under what conditions the population of an entire country changes its behavior radically without the compulsion of open force and violence.” (Mintz 1985, 166) On the basis of my ethnographic research into how a given population gained in stature over the course of single decade, I heartily concur. The understanding of power that best suits my findings is more Foucauldian than Marxist (see Dreyfus and Rabinow 1982; Roseberry 1997 for discussion).

The history of the production of sucrose entwined with a massive and brutal slave trade and with the extermination of indigenous populations and their land rights, while historical changes in patterns of sucrose consumption across English society highlight the creation of a voracious appetite for sweetness, an appetite could be satisfied in many different ways without being sated. Mintz perceives power in sucrose itself, along with all human beings involved in its production and consumption. Mintz therefore transcends understandings of political economy that vest capacity in human beings to the exclusion of all other entities, and that portray human bodies as either powerful or powerless. His

account foregrounds the creation of significance “on high” and “down below” – in, through, and between physical bodies.

While he does not draw upon Foucault, Mintz’s nuanced account of how mass sugar consumption became instilled lends support to Foucault’s analysis of a general – but not wholesale – shift from repressive to stimulative forms of power with the rise of liberalism (Foucault 1977{1975}). Individual human bodies, amassed in populations whose dimensions and characteristics could be reckoned with statistics, became increasingly recognized as key to the creation and exercise of power. Foucault famously claimed that resistance always accompanies the exercise of power, but it is worth recalling that, in addition to conflict and revolt, “*résistance*” encompasses friction, fortitude, and entropy. Nevertheless, anthropologists and social scientists have tended to equate “resistance” with challenges to authority, bracketing other ways of expressing and marshalling bodily capacity (Lock and Kaufert 1998).

True to the Marxist tradition, Mintz depicts power as concentrated in particular institutional “centers.” For example, he opposes “the controllers of society” with “working people” (Mintz 1985, 181). He finds mimesis as well as conflict, however. For instance, “the custom of having a wedding cake percolated down through society” (Mintz 1985, 152). Mintz also highlights ingenuity, constrained by circumstance, in how wage earners and their kin used – and found meaning in – sugar. He concludes that “it would be simplistic to conclude that people ate more sugar after 1850 just because its price declined” (Mintz 1985, 178). Similarly, it would be simplistic to conclude that the diabetic population has gained stature in Canada and elsewhere since 1990 just because their numbers swelled. Such a conclusion would bracket the hopes, the fears, the skills, and the multiple efforts to exploit serendipity that underpin both the recent rise in the number of people diagnosed with diabetes and the grim projections for the coming decades.

By tracking how sweetness and power currently interlace in a particular corner of the “new world” marked by colonialism, liberalism and capitalism, this

thesis continues Mintz's exploration of how consumption patterns reflect and help shape the embodiment of political economy. The data gathered for this thesis support an understanding of power that expressly includes the potential for transformation. Mechanisms through which some people exercise power, if not outright control, over the future ground this inquiry. I examine the salience of a particular marker – the sweetness of blood – as applied to members of populations. In addition to the sweetness of their blood, these people are distinguishable from one another on the basis of such features as age, income status, place of residence, gender, and ancestry. Descriptions of how bodies and their parts articulate in a given here-and-now delimits power; yet power knows few bounds because its effects may extend over time and through space in manifold ways (cf. Roseberry 1997, 44).

In examining the identification, characterization, and differentiation of people with sweet blood, the design of this thesis stems from a Foucauldian “capillary” understanding of power that encompasses stark asymmetries and frank inequalities, while questioning accounts suggesting that asymmetry and inequality divest capacity altogether. My biomedical dictionary tells me that capillaries are the tiny blood vessels that link arteries with veins. The arteries branch until they reach the capillaries, which nourish the cells that comprise the body's organs, one oxygen-for-carbon-monoxide and nutrients-for-waste exchange at a time. Accordingly, to indulge the metaphor, this thesis examines exchange and understandings of exchange that pertain to sweet blood in such organs as state bodies, non-governmental organizations, and private enterprise; it also monitors the pulse of such major vessels as newspapers, television news programs, magazines, and the internet.

### ***Reasons for Living***

In a nutshell, Sahlins marshalled anthropological theory in *Culture and Practical Reason* to criticize “the idea that human cultures are formulated out of practical activity, and behind that, utilitarian interest” (Sahlins 1976, vii).

Defining “culture” as any “meaningful order of persons and things”(Sahlins 1976, x), he argued that symbolism enters into and flows from all human activity. He rejected out of hand that most “economic” of suppositions: that “rational people” know first and foremost their own self-interests, out of which they labour to build a world to suit. Accordingly, he trained attention on how embroidered “beliefs” as much as bare “facts” have contributed to political economy – both as an intellectual tradition and as manifold spheres of activity. “Western” society, he asserted, is unique in three ways: in believing that its society springs from nature, in its dependence on money, and in its universalizing tendencies.

The problematization of sweet blood illustrates the extent to which these qualities hinge upon a particular class of cultural object: statistics. Statistics have undergone technical improvements and they have been widely transmitted as part of numerous efforts to improve knowledge and to improve society. They represent populations, which have material forms, and statistics themselves have material dimensions. Statistics thus both represent and form part of “Western” material culture.

For Sahlins, culture implies shared meanings. Yet, humans need not commune in meanings for symbols to have significance for groups of people. “Even” in small social groups, knowledge may acquire significance because it does *not* have equal purchase among all members (Keesing 1987). Symbolic knowledge consists of representations. Words and objects may represent in the symbolic sense by displacing attention from immediate circumstance in evoking some remnant of history and biography (cf. Sperber 1975). Associations need not be entirely shared for individuals and groups to think and communicate symbolically, using such representations as spoken words, the display of objects, and printed numbers. Thus, people may agree that something or someone is important without agreeing on why. Shared associations, moreover, only partially resemble one another. “The same” people, places, and events are recalled from different perspectives within the folds of distinct biographies. Symbolism permits infinite associations and, therefore, meanings. In the case of statistical projections,

the representations in question refer to “the” future, which people “re-member” in relation to what they already know. Statistics, therefore, partially capture past and future dimensions of experience.

The organization of symbols in and through the physical world, encompassing the sentient body, proceeds apace with the perception and order(ing) of things. The printing press and the computer permit symbols to be reproduced and disseminated with ease beyond face-to-face networks. Similarly, the industrial manufacture and mass distribution of material goods standardize building blocks for meaning, but not the meanings themselves. Indeterminacy in associations with objects contributes to, even permits, their significance across large groups of people.

Foucault seized upon the implications of this human capacity to signify in the absence of consensus, drawing attention to transformations in the art of representation throughout Western history. Ultimately, human beings ultimately became viewed as manufacturers of significance, rather than mediums for divine meaning (see Dreyfus and Rabinow 1982, especially chapters 2 and 3, for discussion). This premise underpins ethnographic inquiries, including the present study. In keeping with the overall approach to studying human phenomena conceived by Foucault, especially as represented in his later works, this study examines ways of knowing that may seem separate and autonomous from its origins in specific human bodies, yet that venerate “authenticity” and “accuracy.”

Sahlins holds fast to the authenticity and accuracy as standards for scholarly inquiry in arguing that human beings come to knowledge but by culture. He criticizes the widespread belief in an economy that operates without recourse to meaning, divorced from embodied symbolism yet derived from an obvious human nature. This belief suggests that anthropological research should occupy a “peripheral” rather than a “central” place within academe – especially the study of small-scale societies thought to be replete with symbolism *because* they lack the economy of thought and motion that “the West” supposedly embodies, but, paradoxically, out of which it seemingly evolved. The intellectual tradition

suggesting that the Western economy and society represent “natural” orders assembled through serial pragmatic action, including accurate representations shorn of subjective symbolism, is without parallel (Sahlins 1976, 210). But, Sahlins argues, “the West” is just as beholden to symbolism as any other culture because pragmatism does not efface meaning, nor dictate action. Rather, people usually do what *seems* best, and what seems best inevitably reflects social relations and inculcated ideas.

Sahlins does not extend his insights about pragmatic construction of order and meaning to “human biology,” that is, to knowledge about human bodies as well as the to the material substrate itself. He acknowledges that “nature is forever supreme” in that human bodies exhibit adaptations, including adaptability; its core functions, among them metabolism, set parameters on what human bodies may become (Sahlins 1976, 168). While highlighting that a posited universal body yields manifold realms of meaning and untold varieties of action, Sahlins does not allow for the creation and application of technologies that alter the conceptualization, the capacities, the materiality, and the life span of human bodies. Yet such changes may give rise to new social distinctions. Moreover, “the body” as an analytic category does not exhibit stability over time and in space. Indeed, different visions of the body, and what it is good for, currently have purchase across “the West,” wherein ideas about what is normal and what is proper routinely undergo shifts mediated by the application of technologies (Hogle 2000; Cussins 1998). Insofar as we inhabit our categories and our categories inhabit us, “the body” twists and turns in the gusts of history.

Sahlins’ insistence that categories yield technologies, not the other way around (Sahlins 1976, 131; after Marx 1954 {1887}), reflects his conception of governance – and culture more generally – as an intellectual project superimposed on concrete, historical circumstances. Yet statistical classifications and calculations, applied to human beings, have a recursive character: they both describe and define. As they assimilate statistics, people may define themselves in terms of diagnostic categories and demographic generations (Hacking 1986). The

generation of “significance” – statistical and otherwise – will need further unpacking to follow Sahlin’s dictum that the discipline of economics and the field of political economy must take the creation of meaning into account.

In highlighting variability in “rational” ways to co-exist and subsist in a given physical environment, Sahlins asserts that people “reproduce themselves as certain kinds of men and women, social classes and groups, not as biological organisms or aggregates of organisms (‘populations’)” (see Sahlins 1976, 168). Here, as throughout *Culture and Practical Reason*, Sahlins argues for the primacy of culture over a stripped-down understanding of “the economy,” and in fine anthropological fashion, takes issue with the “naturalization” of inequality. Paradoxically, he underplays the fact that the population concept has its basis in the very philosophical tradition when he sets out a critique that opposes biological organisms and collections thereof to social “kinds.” Ultimately, he naturalizes biological classification and statistical aggregation. The present thesis, by contrast, examines the use of statistics to conceive “kinds” of people and to reproduce them as members, more or less typical, of populations.

In addition to constituting the only known culture to insist that their thinking and entire way of life springs from nature, Sahlins contends that only “the West” is glued together by money. He argues that, via money, “the economy” assimilates everything and everyone unto itself. In this regard, Sahlins says that money resembles kinship in “tribal” societies. “In bourgeois society, material production is the dominant locus of symbolic production,” as opposed to “the set of social (kinship) relations” (Sahlins 1976, 212). He observes that material and symbolic co-production in “the West” takes place within a variety of institutions, linked through monetary flows and the potential for such flows. In other words, for Sahlins, institutional relationships are of another order than kinship or biology, which are not entirely opposed and which root institutions.

The research for this thesis has led me to revisit this formulation of how monetary exchange and the perceived potential for exchange to link and to differentiate institutions, but in the spirit of Sahlins’ trenchant critique. My

research underlined that money is a pervasive *but not the only* reference point through which to postulate and effect change in “the West.” Since money is not valued purely for itself, but for what it can become, capitalism never boils down into mercantilism. Along with money, the classification and measurement of bodies (age and the sweetness of blood, for example) facilitates the apprehension of needs and preferences under liberalism and capitalism. Money *is* symbolic, through and through. It is no less symbolic for its material trappings (cf. Bourdieu 1980, who treats “economic” and “symbolic” capital as distinct, albeit linked, forms of wealth).

The argument that “money is to the West what kinship is to the Rest” (Sahlins 1976, 216) takes on heightened importance when pausing to appreciate that “biology” denotes a instability over time and across cultures – a point that Sahlins broaches but does not develop in such examples as variability in colour perception, in definitions of edibility, and in clothing. As illustrated by Sahlins’ conclusion about the centrality of money in “the West,” one of the notable features of anthropological scholarship on valuation and exchange is the persistent and often explicit use of “our” economy and kinship system as a point of comparison. Weiner provides a particularly poignant case in point, which brings Sahlins’ comparison of the money-based “West” with kinship-based societies into sharper pitch:

Trobriand exchange objects, unlike Western money, cannot be detached from the human experience of regeneration and immortality. They are not alienated from the basic concerns of society and therefore social relationships are not merely relations between impersonal things, in Marx’s terms, but remain relations that reify the cyclicity of life, death and rebirth. Thus, Trobriand women or men, exemplified in the objects they exchange, perceive the value of each other through the interface of the value of human beings and the value of regensis. (Weiner 1976, 231)

Similar to Trobrianders, says Weiner, “we” engage routinely in exchange; but “we” do not live for exchange; “we” simply exchange to live. Somehow, money stands outside our “basic concerns” – sickness, health, death, and regeneration. Moreover, money ostensibly remains impersonal, detached from our bodily existence and sense of kinship with others, even if the things that we give up money to obtain shape our everyday existence and our very bodies, as well as lending material form to hopes for the future.

In this thesis, money surfaces in statistics that may, under certain circumstances, legitimately define the value of human lives in a Western, liberal democracy. More generally, this thesis finds that counting (money, the amount of glucose in a modicum of blood, the members of the diabetic population) helps cement the value of human lives under liberalism. Yet, counting alone cannot confer value because counting presupposes classification, as well as a unit of measure. In the history of anthropology, much ink and debate has been devoted to the classification and evaluation of people via kinship terms and norms. My research raises questions about the classification of people under liberal capitalism that recall questions that anthropologists have posed about the kinship systems of other societies. To what extent is one person like another? What makes one person more useful or worthy than another? How do people conceive the past and reproduce systems with a time-scale far longer than the individual human life? Anthropological scholarship on kinship and on exchange raises such questions, but only if one sets aside many truisms about Western society underpinning this literature. The most pernicious of these is the crux of Sahlins’ argument, namely, that Westerners insist that the “the economy” occupies a sphere separate from culture, such that “Western” technological innovation, institutions, and exchange patterns appear as “meaningless” ways of fulfilling human needs. From this perspective, research based in “non-Western” cultures seems mainly to provide a series of illuminating contrasts with Western economics and politics, with little common ground.

And yet, felt desires other than for money itself fuel capitalism – as demonstrated by such modern-day “hucksters of the symbol” as market researchers, fashion designers, and advertising agents, (Sahlins 1976, 217). In other words, “demand” stems from desiring “a style of life” as well as the rudiments of existence, and these desires can be stoked. That said, “life chances” are hardly uniform, which liberalism certainly acknowledges: debates regularly center around what might “reasonably” be done in light of knowledge generated about “the market” and about various human populations.

Rather than seeing money as *the* be all and *the* end all of Western society, this thesis highlights that “life itself” may represent a standard of value of at least equal salience (after Foucault 1976; Foucault 1994 {1978}). Notably, moral sanction and regulations limit the conversion of anything and everything into money: “Western” democracies forbid slavery and monetary payment for bodily organs, for example. Liberalism construes money as a tool that may secure, enhance, and even extend “life” so long as others do not suffer (“too much”) in the process.

Besides its heavy reliance on money and the illusion that it comprises a series of natural orders, Sahlins argues that “Western” society is unique because “it responds transformationally to events, incorporates historical perturbations as structural permutations, according to a general code of significance.” (Sahlins 1976, 220) Careful to underline that “tribal peoples are capable of the very same transpositions and reformulations of symbolic code,” Sahlins locates the unique nature of Western philosophical tradition in that it purports to explain *all* of human history and incorporate the entire contemporary world, along with its future. Thus, its explanations of “the economy” and “history” strive for universal applicability.

Ironically, the quest for universal meaning, including the material forms that this quest takes, may appear to be entirely “natural.” Western economic theories routinely imply that “individuals rationally bent upon their practical interests” may dispense with symbols, but the “elaborate and statistical offspring”

of Western civilization are no less cultural because they quantify (Sahlins 1976, 220). To this I would add that numbers *are* symbols, through and through, including when displayed in columns in “the West” or as heaps of yams in the Trobriand Islands. The display of printed numbers permits economies of greater scale, however.

This thesis examines some of the “elaborate and statistical offspring” wrought through measures of human bodies taken by researchers, clinicians, and patients-*qua*-citizens-*qua*-customers. That these measurements pertain to longevity and quality of life (seemingly “natural” ends for any social system) should not blind us to historical and cultural specifics that inform how “we” count, classify, and hope. This thesis argues, *pace* Sahlins, that some significant features of “Western” institutions remain taken for granted by many anthropologists and others familiar with “the West.” The process of carrying out the research for this thesis convinced me of that. I am not convinced, however, that “everything in capitalism conspires to conceal the symbolic ordering of the system – especially those academic theories of praxis by which we conceive ourselves and the rest of the world” (Sahlins 1976. 220). Perhaps I am unduly reassured by the fluorescence of theory on bodily practice and the contingencies of governance that have appeared since Sahlins opined the state of the world and the state of academe. Perhaps I also invest overly in signs of market instability that regularly make headlines.

## ORDERING THINGS

As an ensemble, this thesis illustrates some ways in which “science,” “politics,” and “the economy” flow through human bodies and representations thereof. Although my methods and questions inevitably draw upon a “Western” philosophical tradition, this research project reflects serial efforts to detach my inquiry from norms and categories that secure conventional knowledge in and about “the West.”

Following an account of the field research undertaken for this project (Chapter 2), the thesis divides roughly into two parts.

The first part (Chapters 3 through 5) focuses on the generation and circulation of knowledge about sweet blood within biomedical circles; the second part (Chapters 6 through 8) traces how biomedical knowledge about diabetes surfaces in government policies, public relations campaigns waged by diabetes organizations, media coverage of diabetes, and the marketing of diabetes-related products. This analysis highlights that “Canada” *sometimes* constitutes a single, meaningful geographic and political unit, and that biomedical knowledge about diabetes both unifies and divides populations marked by sweet blood.

The distinction between the “inside” and the “outside” of biomedicine that helps structure this thesis is more heuristic than absolute. Leading biomedical researchers occupy a distinguishable realm marked by professional training and titles, attendance at certain gatherings, mutual friends and acquaintances, and specialized skills and vocabulary. Nevertheless, biomedical knowledge and practice is part and parcel of Canadian society – a veritable army deploys and absorbs biomedical knowledge. Some, but by no means all, of these people inhabit bodies suffused with sweet blood. This thesis focuses on why sweet blood currently matters to so many people who have *not* been diagnosed with diabetes, but to do so, it must account for what sweet blood implies for people with this condition.

## 2. Positioning the Ethnographer

This study involved observing phenomena transversally, across space and time (Abélès 1995; Marcus 1995; Shore and Wright 1997). This methodological approach is *de facto* comparative in that the ethnographer cannot but compare what is said and done in a particular place at a particular point in time with what has already been observed elsewhere (Houdart 2000 for an adroit discussion). Yet the ethnographers' comparisons do not involve inherently standard units. The research process itself helps shape and bound these phenomena, through such standard practices as coding the transcript of a forty-minute tape-recorded interview.

Ethnographers produce, gather, and then must distil mounds of documents: formal fieldnotes but also such things as miscellaneous bits of paper, brochures, video cassettes, audio cassettes, and, these days, print-outs of web pages and email messages. To make sense of it all, in a fashion, ethnographers draw upon bodies of scholarship as they collect and analyze their data. Contributions to the anthropology of economic systems, the anthropology of political systems, the anthropology of cognition, the anthropology of biomedicine, and sociological and historical studies of science and technology inspired this thesis. These research areas have distinct histories, which only partially overlap. Ultimately, their differences as well as their similarities have helped me write.

### PEOPLE, PLACES AND TIMES

For this ethnographic research project, the network under study is comprised of diabetes researchers and people affected by diabetes research in Canada; this includes people with diabetes, people “at risk” for diabetes, government officials, representatives of relevant organizations, community leaders, and health professionals. By interpolating humans with a diverse range of technologies, this network achieves a certain form, which is never static but

nevertheless can be said to exist, for members routinely refer to “the diabetes community” and “the diabetes world.”

I conducted the bulk of my field research from September 1999 through June 2000 in three Canadian provinces (Alberta, Ontario and Québec). Occasionally, the research stretched yet further afield. I traced connections and trends back in time by collecting retrospective accounts and amassing archived materials (audiotapes, videotapes, transcripts, paper documents). I also conducted preliminary research (participant-observation and document analysis) intermittently from October 1998 through May 1999, and I conducted supplementary and follow-up research on select issues from October 2000 through July 2001.

This project mainly involved unobtrusive research (Webb et al. 1981 {1966}). I positioned myself to watch, read, and listen with the goal of theorizing how knowledge about diabetes takes form and travels. Unobtrusive researchers may study what people inadvertently leave behind them, but I mainly relied on sources placed deliberately in “the public domain.” Public statements by professionals may not constitute “everyday talk,” but for some, they are common occurrences (cf. Atkinson 1995). Speaking before an audience, the preparation of materials to aid oral presentations, and writing for publication constitute routine activities for the professionals who feature prominently in this thesis. To complement my unobtrusive observations, I conducted formal interviews with 25 professionals, entered into informal dialogues with over 60 professionals, and attended two workshops designed to educate adults and adolescents with diabetes about their condition.

The emphasis in my project on communication *among* professionals departs from the tendency among social scientists who study biomedicine as a historical and cultural phenomenon to focus on clinical encounters between professionals and patients. In emphasizing professional-patient interactions, this line of research often attributes to biomedicine the features of a homogeneous cultural system marked by the person of the clinician, contrasted with a “folk”

counterpart embodied by the patient (Atkinson 1995, 130-131; Ferzacca 2000). Instead, this project bespeaks diversity, hierarchy, and even dissent within biomedicine – paradoxically, through efforts to reach consensus about how best to redress diabetes. It also reveals concrete and intricate connections between biomedicine and institutions such as governments and charities.

Extending anthropological research on clinical compared with lay notions about diabetes (Ferzacca 2000; Loewe and Freeman 2000; Sunday, Eyles, and Upshur 2000), as well as historical studies of the interface between diabetes research and clinical practice (Bliss 1982; Feudtner 1995; Marks 1997; Sinding 1999), this thesis finds that the circulation of knowledge about diabetes in the public domain endows social values with obdurate forms. With the aid of biomedical and statistical technologies, the bodies of people with diabetes are made to express, in numerical terms, norms and departures from these norms. So rendered, diabetic bodies mediate connections between diabetes researchers, governments, charities and clinics.

This thesis examines *rhetorical practices* employed by researchers and other professionals whose work implicates people with sweet blood and people “at risk” for developing this condition. By rhetorical practices, I mean speech, writing, imagery and numerical figures that take diabetes as their object and that aim to please and to persuade. This understanding departs from conventional definitions of rhetoric in that it includes images and numbers alongside speech and writing because words do not always persuade on their own – certainly not when science is involved.

In scientific publications and presentations, researchers seek to persuade readers that their words are true to their observations, as congealed or “inscribed” in tables, charts, photographs or diagrams (Bastide 1990; Latour 1990; Myers 1990). The images are supposed to allow readers to judge for themselves, thus enhancing credibility and persuasiveness. Often, because quantification has become such an important feature of scientific practice, these images contain or represent statistics.

Very often, as Strathern alleges for anthropologists who study exchange systems in Melanesia, anthropologists who encounter statistics “have been dazzled by local rhetoric: by the precision of counting, by the quantitative displays, by the close records kept of transactions. We look at the counting, and overlook what the counting is for” (Strathern 1992a, 171). Statistics not only serve rhetoric, they *are* rhetorical through and through. Classifying and counting “makes up” classes of things, including people-as-things (Hacking 1986). In science as much as in Melanesian exchange, counting does not “merely” aggregate. Counting involves classification, bestowing value by highlighting similarities and differences.

Rhetorical practices such as statistical calculations and displays do not “construct” the past, present and future from whole cloth because writing, speaking, drawing and counting interface with “the reality at hand” in manifold ways. For example, the degree to which general practitioners and patients follow recommendations for controlling diabetes varies. Indeed, I learned that diabetes researchers often rhetorically refer to “compliance” as a thorny problem when buttressing certain recommendations, such as more “user-friendly” insulins. That is, they incorporate some departures from their rhetoric into their rhetoric. This study does not attempt to assess the extent to which practical activity reflects or departs from scientific rhetoric about diabetes. Rather, I investigate how rhetorical practices that describe the impact of sweet blood draw upon and help shape values. I regard rhetorical practices as part of moral economies that encompass scientific research and whose suasion derives from ambient, historically-contingent circumstances (following Daston 1995).

The rhetoric analyzed for this thesis also remains resolutely tied to certain “types” of bodies: those with sweet blood, the hallmark of diabetes. Indeed, by analyzing rhetoric invoking diabetes, this thesis is tied to sweet blood too. I seek to understand how rhetorical practices have positioned diabetes in public debates and in discussions among mandarins about such matters as the responsibilities of the state, the physician, and the citizen. That is, this thesis analyzes the discursive

status of diabetes, which simultaneously expresses and configures concrete material realities. My examination of rhetoric about diabetes highlights traffic in knowledge about human worth and needs, including arguments about the benefits of diagnosis. Discourse may help bring into being its very objects analyzed (Foucault 1971 {1970}), but not if the people and things so-conjured refuse entirely to cooperate. This is as true of my research project as of any other, and this is what lends it truth. To explicate further how I went about my research and what I found, I turn now to how I came to fix my object of analysis: rhetoric invoking diabetes in contemporary Canada.

### **ACQUIRING AN INTEREST IN DIABETES**

The decision to focus my doctoral research on diabetes stems from a two-day workshop, held in October 1998 on the Flathead Reservation nested within Montana, on the implications of recent developments in genetic research for Indigenous peoples. A mix of about fifty “tribal leaders, scientists, bioethicists, tribal attorneys and educators” (Harry 1999), mostly based in the United States with a sprinkling from Canada, attended this workshop. From the opening prayer, participants expressed anxiety about the implications for Indigenous peoples of the many attempts underway to classify populations and chart migrations using genetic technologies. Genetic research on Indigenous people could threaten already-tenuous legal rights to land and undermine traditional teachings about Indigenous origins, said several presenters.

Concern gave way to anger whenever the Indigenous activists spoke of the Human Genome Diversity Project (HGDP), which they did frequently. The HGDP, an initiative conceived in 1991 to bank and study genetic material from so-called “isolates of historic interest,” quickly garnered protest from Aboriginal leaders world-wide (see Lock 1994 for an overview of the controversy). The workshop organizers had issued “repeated invitations” to representatives of the HGDP and offered them an opportunity to speak at the workshop, but in the end, no one from the project attended.

Late in the morning of the first day of the workshop, as part of a panel on “Genetic Projects of Concern to Native communities,” Debra Harry, an organizer with the Indigenous Peoples Coalition against Biopiracy, lambasted the aims of the HGDP and the poor manners of the scientists involved. Following her barn-burning presentation, a representative of the United States’ National Institutes of Health (NIH) “helped the assembly understand the distinction between the Environmental Genome Project and the HGDP” (Harry 1999). His presentation began with a slide that read “Studying Genetic Variation: Medicine versus Anthropology.” Unlike the HGDP, the Environmental Genome Project sponsored by the National Institutes of Health in the United States focuses on health risks arising from the interaction of genes and the environment, he explained. This project would study genetic samples from several ethnic groups in the United States, including “Native Americans.” Midway through his presentation, he underlined that gene-environment interactions play a significant role in diabetes, which, other presenters had already noted, afflicts disproportionately Indigenous peoples. “All of us value public health, but not all of us want to reconstruct history,” this NIH representative said to sum up.

I was stunned to see that the evocation of improved health status diffused much of the anger conjured by the HGDP. The promise of an improved understanding of diabetes among Indigenous peoples seemed especially alluring. While worries and concerns surely remained, many of the Indigenous people assembled seemed willing to at least consider genetic research, if it might help prevent or treat sweet blood in their midst.

### **INTEREST COMPOUNDS: DIABETES IN THE NEWS**

Weeks later, a journalist friend referred me to a report on this conference that appeared in the *Globe and Mail* (see Abraham 1998a). This item on the burgeoning “aboriginal movement defending genetic rights” served as a sidebar to a feature story about a genetic research project on diabetes underway in an Aboriginal community in Northern Ontario (Abraham 1998b). The *Globe and*

*Mail* reported that the community featured in the article, Sandy Lake, has the third-highest prevalence of diabetes ever seen, but as few as thirty years ago, the disease was unknown in this population. Entitled “Let’s make a DNA deal,” the article was assigned a high-profile placement (it began below the fold on the first page) and it focused on the relationship between the community and the research team. This article kicked off a week-long series of features on the social and financial implications of genetic research. It began:

Not so long ago, potatoes and turnips were the only produce available in the grocery store in the remote community of Sandy Lake, Ont. Now, there are rows of green peppers, broccoli and leaf lettuce.

It was part of the deal. The Oji-Cree who live there made sure of it. (Abraham 1998b)

The article quotes the Deputy Chief as saying, “People were just sick of research projects, being asked questions and never seeing any return on that.” Then it spells out the terms of the agreement between the community and the research team:

In return for residents giving researchers samples of their DNA to unearth the genes responsible for their diabetes epidemic, the band council asked for fresh food, expanded medical services, special school programs and royalties from any cash that flows from the project.

They got it all. (Abraham 1998b)

My interest was piqued because the article seemed to affirm the observation at the Montana conference that health concerns could trump Indigenous peoples’ worries about (genetic) research. And once again, attention centred on diabetes.

An editorial that appeared a few days later, in the weekend edition of this paper, fuelled my interest. The editorial was given the heading, “Genes for sale,” and began:

We have been reading with a continually expanded mind Globe and Mail reporter Carolyn Abraham's series on the implications of genetic research for the health and wealth of Canadians.

But we're troubled by one of her discoveries. She described the efforts of a group of Ontario Cree [sic.] to wrest benefits from scientists seeking to identify the gene defect that causes 25 percent of the tribe to be diabetic. If you want to study us, the Cree band council said, you have to pay us: fresh food, expanded medical services, special school programs and royalties from any cash that is made by the project. (Globe and Mail 1998)

According to the editorial, "this model of a monetary relationship between the sick and the scientists is problematic" because the people enrolled in the study will benefit most from any cure or treatment derived. Therefore, the editorial holds that "the sick" should give freely to genetic researchers; in return, the scientists could provide "free access for a period of time to drugs or tests that may result from the research."

This editorial commanded my attention for several reasons. First, of the five articles in the series about how the implications of genetic science for human health and for business, the editorialists singled out the agreement between an Indigenous group and researchers for derision, underlining that the place of Indigenous peoples in Canada remains contested in many quarters. The editorialists held that gift exchange constituted proper comportment in this case, and that any exchange involving or even bordering upon monetization would propel genetic research down the proverbial slippery slope. Given the pro-business reputation of this newspaper, I was surprised to read that monetization was inappropriate when researching human health. More specifically, the editorial decries monetary or in-kind benefit for research subjects, but not for companies. Still, it seemed that health was accorded a special status, so precious that it is priceless. At the time, I was dipping into anthropological scholarship on "need" and exchange in relationship to biomedical technologies, and so the editorial's condemnation of bartering genetic material caught my attention. The expressed

preference for gift exchange in this instance also intrigued me: according to the editorial, a gift of genetic material might morally compel scientists to furnish improved medical technologies developed through use of this material, for a period of time.

The residents of Sandy Lake should gladly hand over their DNA to researchers, claimed the editorial, because “they are less like people finding oil under their meadow and more like a farmer who wants the government to help him with a dike so his farm isn’t constantly flooded.” (Globe and Mail 1998) As harbours of disease, they are more akin to those desiring public relief than to those in a position to provide access to a valuable resource, according to this editorial. The equation of scientists with governments struck me as curious. Further, the entire community was assigned the sick role in that exculpation would hinge upon their co-operation with the medical researchers, even though most residents did not (yet?) meet the diagnostic criteria for diabetes. The editorial erases the distinction between those with and without the condition, labelling them all as “the sick.” Indeed, the editorial portrays diabetes as genetically-determined, even though the researchers quoted in the original article underline that the diabetes epidemic in this community is a very, very recent phenomenon. Sweet blood now afflicts so many in this community, these researchers maintain, because changes in diet and physical activity introduced through contact with white society unmasked a predisposing genotype, producing “a foul stew” (Abraham 1998b).

With diabetes cast as a genetic destiny for the residents of Sandy Lake, the editorial decries fresh fruit and vegetables, health promotion in the local school, and expanded medical services in the community as a “pay-me-for-my-DNA schema.” (Globe and Mail 1998) This characterization ranked because improved food choices and the instilling of healthy habits in the community’s youngest residents might help prevent diabetes from developing in the first place. In addition, I wondered if better medical care might prevent or delay what the editorial describes as the residents’ “immediate problem[s]” of “blindness, heart

disease, amputated limbs and other life-shortening effects of the disease they call Sho-go-way-pee-nay,” the sugar disease.

This editorial, the article upon which it drew, the sidebar on the workshop held in Flathead country, and the experience of attending this workshop highlighted that genetic research on diabetes among Indigenous peoples could stir passions. It was apparent that the impact of diabetes on Indigenous peoples had enlisted the energies of many others, including scientists, physicians, and journalists. Each of these sources underscored that responses to genetic research have not developed in a vacuum. Therefore, when I ultimately decided to focus on sweet blood for my doctoral research, I wanted to design a project that would examine the generation and circulation of knowledge about diabetes, including but not exclusive to genetic research into diabetes and research on diabetes among Indigenous peoples.

### **INTEREST AND CAPITAL: THICKENING THE PLOT**

I decided not to focus squarely on diabetes among Indigenous peoples partly because I was interested to learn that the epidemic proportions of the diabetes problem in Sandy Lake had failed to elicit financial support from pharmaceutical companies. Indeed, a protracted search preceded commitment from a single public funding agency. The NIH in the United States was the first to fund research into diabetes in Sandy Lake, in the amount of US \$25,000, after provincial and federal funding agencies in Canada had turned down the researchers' requests. Once the researchers had some American funding in hand, Canadians reconsidered. As of 1998, provincial and federal governments had provided close to \$1-million.

Part of the funding went to a diabetes prevalence study, which found that over 50% of those over 50 years of age had the disease (Harris et al. 1997). Indeed, the study bestowed upon Sandy Lake the dubious honour of the third-highest diabetes prevalence ever reported, after two other Indigenous groups: the

Pima of modern-day Arizona and the Naurea in Micronesia. Nevertheless, as reported by the *Globe and Mail* and confirmed in subsequent interviews conducted for this research project, “no drug company will bite. The suspicion is that genes linked to diabetes in the Oji-Cree are unlikely to yield a promising therapy for the general population.” (Abraham 1998b)

In the estimation of the pharmaceutical companies approached, the exact nature of the diabetes in this population is likely sufficiently distinct for knowledge derived from its study to have application only for the study subjects, their immediate relatives, and, perhaps, other Oji-Cree communities. Indeed, as discussed in further detail in Chapter 5, the Oji-Cree population has been found to be sufficiently different in genetic terms from other human populations for members to have developed their own particular variant of diabetes. The researcher heading up the genetic component of the project, Dr Robert Hegele, is not disappointed in the lack of support from pharmaceutical companies because “[i]ndustrial funding usually comes with strings attached; there are conditions on the reporting of findings and scientific autonomy.” (cited in Abraham 1998b)

After the *Globe and Mail* feature on genetic research into diabetes in Sandy Lake appeared, I conducted MedLine searches for each of the researchers cited in the article. From the MedLine search results, I discovered that one of the researchers was listed as a co-author for the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada*, sponsored by the Canadian Diabetes Association and published by the *Canadian Medical Association Journal* in October 1998 (Meltzer et al. 1998). After downloading the document itself, I learned that another of the Sandy Lake researchers had also been involved in their development.

In February 1999, as part of the governing Liberals’ annual budget, the Canadian government announced \$55-million over three years for a diabetes strategy (Canada. Health 1999a). This announcement reinforced my resolve to focus on diabetes for my doctoral thesis. To investigate the generation and circulation of knowledge about diabetes, I seized upon the *1998 Clinical Practice*

*Guidelines for the Management of Diabetes in Canada* and upon the 1999 Canadian budget as two documents, cultural objects, worth unpacking.

At the time, I imagined that these two developments might be part of a chain reaction, based on previous experience as a researcher in a non-governmental organization charged with analyzing and influencing public policy. The *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* made several prescriptions for health policy, so it seemed plausible that they had been used as a lobbying tool. My investigation revealed that medical research did play an important role in securing additional Federal funding for diabetes, but not the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* specifically (see Chapter 6).

To explain why I thought that the publication of the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* and the 1999 Federal promise to “do something” about diabetes might have been tightly linked, allow me to say a few words about clinical practice guidelines (CPGs) and their place in the health care system. CPGs are “systematically developed statements to assist practitioners and patients in arriving at decisions on appropriate health care for specific clinical circumstances,” according to an oft-cited definition promulgated by the United States Institutes of Medicine and endorsed by the Canadian Medical Association. As such, CPGs are clinical policy documents in which specialists propose rules to govern fellow physicians (especially general practitioners) and their patients (Lomas 1993). Further, as prescriptions for clinical practice, CPGs have significant ties to public policy; the pharmaceutical regimes recommended in CPGs may not be covered through public health insurance, for example. Not surprisingly, clinical practice and public policy routinely depart from CPGs. During the 1990s, the increased emphasis on evidence-based medicine led to the creation of a veritable CPG industry.

At “multidisciplinary summit” convened in June 1999 in a Toronto hotel to “script a future” for CPGs in Canada, a “100-odd representatives of patient groups, practitioner groups, and administrators of health care entities” including

pharmaceutical companies and hospitals, spoke to the increased popularity of CPGs (Health Policy Forum 1999). Some regarded the popularity of CPGs as cause for concern. In the preface to the published proceedings of this summit, Calvin Gutkin, the Executive Director of the College of Family Physicians in Canada observed:

Over the past decade, enthusiasm for clinical practice guidelines has exploded and thousands of so-called clinical practice guidelines (CPGs) have been developed. Despite this fact, guidelines are still not clearly positioned within the overall strategy of health care delivery. Indeed, many vitally important questions lurk in the shadows of the international CPG movement. For instance, when looking at the context of managed care in the U.S. and health care reform in Canada, one might ask whether CPGs are driven by the goal of producing better outcomes or by the cost-saving objectives of third parties. Similarly, are CPGs a help or a hindrance to health care professionals and providers? Do they offer medical-legal protection, or are they potentially incriminating? Are they, or should they be, based on scientific evidence alone, or can they be based on experience and anecdote? Should they be developed by and made accessible to all health-care professionals and patients or should they be physician-developed and oriented? How do they impact on the doctor/patient relationship? (Health Policy Forum 1999, 3)

He also said that by the mid-nineties, his organization refused to become “a guidelines factory.” Instead, the College directs members towards available guidelines, advises them on their assessment and use, and helps disseminate CPGs that have already been developed and endorsed. In part, the College reached this position out of concern for redundancy and competition between guidelines from different organizations, but also because guidelines are so expensive to develop, he explained.

The *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* were extremely helpful to me in carrying out this research project. They summarized “the state of the art” in diabetes research, they tailored this global knowledge base to the Canadian population and health care system, and they pointed to people and institutions crucial to the generation and circulation of knowledge about diabetes in Canada.

### ON TO OTTAWA

The next significant event in the shaping of this research project was attending the 1999 Canadian Diabetes Association (CDA) Professional Conference, held October 13-16 in Ottawa, Ontario, the capital of Canada. By this time, I was ready to begin fieldwork in earnest. Leading up to the CDA conference, through library research and my social network, I identified a number of researchers and health care providers across Canada whom I wanted to meet, and I soon realized that nearly all of them would attend this conference. Efforts to set up a meeting with researchers who, like me, are based in Montréal impressed upon me the significance of this gathering for my research. We’re extremely busy over the next few weeks preparing for the CDA conference, I was told. When I mentioned that I would attend the CDA conference, it was suggested that we meet there instead. Thus, even contacts across town perceived this conference as an appropriate venue for a meeting.

My name tag and conference bag allowed me to mingle easily with the assembled. I witnessed a collectivity take shape whose members hail from across Canada, with a sprinkling of invited guests from the United States and Britain mixed in. While this gathering occurs but once a year, many members remain in touch with one another on a regular basis. One physician-academic, next to whom I sat at a luncheon during the 1999 CDA professional conference, told me that my research project made him reflect on why he attends professional meetings. One reason that he had come to this conference was to meet up with his co-investigators in an on-going random trial. Email and conference calls are fine for

getting the work done, but periodic face-to-face contact helps keep things going, he said. The second reason was to meet up with his son, who was attending a university far from home but within a few hours by train from the conference site.

This conference highlighted linkages between private industry, non-governmental organizations, governments, research and clinical practice in problematizing sweet blood and suggested some measure of their relative strength. I explored these linkages in greater depth in interviews with contacts established at the conference. Indeed, I conducted four formal interviews on site, only one of which was arranged in advance of the conference.

One of my objectives at the conference was to distil what “drives” diabetologists. This objective emerged through a series of collegial discussions. Compared with cancer, which had been the original focus for my doctoral research, a diagnosis of diabetes does not tend to strike dread into the heart of the patient, a clinician colleague observed. One of my PhD committee members pointed out that diabetes seems to have less emotional suasion than, say, leukemia or Huntington’s disease. Further, since it tends to strike during childhood, type 1 diabetes seems to have greater emotional appeal than type 2. Yet type 2 diabetes accounts for 90% of all cases. By extension, I suspected that a good many of those gathered for the CDA conference would mainly treat or research type 2 diabetes. At the close of the second day of the conference, during a presentation about “Diabetes in the New Millennium” sponsored by Bayer, I scribbled in my field notebook that perhaps the over-riding concerns informing the work of these diabetes professionals are longevity and quality of life. Further research revealed that the *extent* to which diabetes is currently known to compromise longevity and quality of life has played a crucial role in establishing diabetes as a social problem in contemporary Canada.

## BACK AND FORTH IN TIME

Although I did not know it at the time, one small booth set up in a corridor of the Ottawa conference centre for the duration of the 1999 CDA Professional Conference would lead me to a veritable trove of ethnographic data. Audiocassettes of the presentations were available for purchase at this booth because presenters had consented to have their sessions taped and for these tapes to be sold. I spotted this booth mid-way into the conference, but decided to leave the final selection (at \$12 per tape) until the final day. Many others in attendance had the same idea. Immediately following the conclusion of the conference, I had to wait in line for over fifteen minutes before a harried clerk could process my order.

Upon my return to Montréal, I began to transcribe tapes of key sessions that I had attended at the 1999 CDA Professional Conference, permitting a more thorough analysis of their contents. As speakers frequently invoked clinical trials, pharmaceutical products, and biomedical terms with which I was not familiar at this early stage of the research, I found it useful to rewind, pause, and even fast-forward in relation to my own goals and knowledge level. Obviously, these possibilities did not exist while listening to the lectures and question-and-answer sessions on site in real time.

I found the tapes so useful that I called the company awarded the contract to record sessions at the 1999 CDA Professional Conference to find out if this company also held the contracts for previous CDA conferences. To my delight, the 1997 and 1998 tapes were still available for purchase. From the conference programs, I identified several sessions that were pertinent to my research project. I could not attend the 2000 CDA Professional Conference in Halifax, Nova Scotia, but I did order tapes of select sessions. Thus, I was able to follow key developments through over sixty hours of presentations and dialogues at CDA Professional Conferences, 1997 through 2000.

The availability of these tapes complemented other data collection sources and strategies. For example, the penultimate version of the *1998 Clinical Practice*

*Guidelines for the Management of Diabetes in Canada* on diabetes were presented at the 1998 CDA Professional Conference, just days before their publication in the *Canadian Medical Association Journal*. A draft version of these guidelines was presented at the 1997 CDA Professional Conference during a marathon session that clocked in at more than three hours. Analytically, overlap between the oral presentations and the written abstracts in the conference package helped me understand key issues, and indeed, which issues were perceived as key.

Such things as tone of voice and questions from the audience alerted me to significant issues and significant players. By referring to a directory of professional members obtained at the conference, I was often able to identify the speakers, locate them geographically, and ascertain their professional speciality. In these ways, analyzing the conference sessions helped me identify questions to pose during interviews and helped me determine whom I would interview. Some voices and names recurred frequently, marking them as potential interview subjects. In other instances, my purposes were served without conducting a formal interview.

The CDA professional conference tapes helped me focus my attention on interactions among diabetes researchers, physicians, and other professionals on a Canada-wide scale, and also helped me locate developments in Canada within a global frame of reference. Without them, this project would have taken a very different turn. The tapes allowed me to stretch, contract, and witness events through time.

Given the importance of CDA professional conference sessions as data sources for this thesis, I should say a few words about their format. Most presentations last twenty minutes to half an hour, and are organized by theme into panels. Plenary sessions tend to exceed forty-five minutes. Visual aids (usually slides but occasionally overhead transparencies) accompany the oral presentations. The speakers never read their presentation, but key their remarks to their visual aids. Thus, the visual aids prepared in advance ground the presentation, but the speakers improvise the exact words of the presentation on

the spot. Certain slides, such as landmark clinical trial results, tend to recur from presentation to presentation. Such “classic” results may provide a context for interpreting the significance of the new findings presented by the speaker, for example. At the end of the presentations, members of the audience may approach microphones placed in the aisles to pose questions to the speakers or provide commentary.

### **TIMES AND PLACES FOR TALK**

In addition to CDA professional conferences and the workshop on Indigenous rights in regards to genetic research, four other conferences and workshops that I attended during the course of fieldwork proved helpful to my research. None focused specifically on diabetes, but all three dealt with health matters. Presentations by an executive with a public opinion polling firm, by academic researchers, and by government officials were among the presentations that proved to be useful data sources.

Besides presentations at conferences, I analyzed texts of prepared speeches delivered by politicians and senior bureaucrats as well as press releases containing excerpts of such speeches. I gathered and carefully examined these documents for two reasons, one practical and the other epistemological. First, I was not present when these speeches were delivered. Second, in that this thesis concerns the fashioning of rhetoric, such prepared statements are highly relevant.

Interview subjects were chosen both through deliberation (that is, after reviewing documents and transcripts from CDA meetings) and through snowball sampling. Time pressures reared their head continually while scheduling and conducting interviews for this project. To demonstrate respect for their status and to make the most of the limited time accorded me for an interview, I needed to be well-prepared and punctual. Listening to conference presentations, reading scientific articles, and reviewing web sites aided interviews with diabetes researchers and other professionals. One diabetes researcher, at the close of an interview conducted just a few months into the fieldwork, commented on my

“biological literacy” and asked if I have a background in biology. I do not, but I was pleased to have conveyed this impression.

Being interviewed was not a novel experience for many of the 25 professionals formally interviewed for this project, although usually the person wielding the tape recorder is a journalist, not a social scientist. On several occasions, I spied copies of newspaper articles hung on the walls of hospitals, clinics, or laboratories that featured quotes from people with whom I had scheduled or completed interviews.

As busy people juggling many priorities, the professionals interviewed for this project could not spare much time to serve as this ethnographers’ informants. This message came in particularly loud and clear midway through an interview with one physician, when the phone rang and I was asked me to turn off the tape. After a brief conversation, the physician replaced the receiver, and said, kindly, “I’ve got several dying patients right now. I’ll try to protect this time but there are no guarantees.”

Twice I arrived for an interview earlier than physician-interviewees were expecting me, which further underlined how minutely these professionals portion out their time. On both occasions, the physicians in question immediately checked electronic sources to verify the scheduled time. Here is an excerpt from my fieldnotes documenting the first of these occasions:

At 4 P.M., I present myself to [his] secretary. I can see [him] in the next room; the door is half-closed. I tell her that I have a 4 P.M. appointment. She says, ‘You’ve been rubbed out.’ And then she gets up to check with [him]. He tells me that I’ve made a mistake. He originally had been down for the 14th, but when I emailed to confirm, I said the 15th, ‘And today’s not the 15th.’ He goes on to say, ‘I’ve got the evidence,’ opening up the email in question and reading it aloud! Melanie Rock feels about 1 inch off the floor. Then there’s the evident quandary: can he fit me in or not? I ask if tomorrow is still OK. And he says that he is

swamped, as they've got to get a grant in – he says this as he strides by me and checks the appointment book.

I am waved in to the office; he remains outside, conferring with his secretary for a couple of seconds. I take advantage of this time by trying to collect myself – my notes, my thoughts, my composure.

As he takes his seat across the desk, he says, 'Shoot.' And then he adds, 'I just don't have much time.' I'm on.

On the other occasion when I arrived early for an interview, I presented myself to the reception desk by 10 A.M. After the receptionist alerted the physician, he told me, "Oh, I had you down for 1," meanwhile fishing out of his lab coat an electronic organizer, which was just a tad bigger than a credit card. Tapping at the screen with its pencil device confirmed that he had me scheduled for 1 P.M.. Inwardly I cringed, even though (this time) I was confident that I had noted the time correctly. I offered to return at 1 P.M. The physician checked his basket, which contained just one chart. I could meet in about half an hour, he said. So I waited.

As signalled in the paragraph above, I took copious notes on the process leading up to each interview, which generated many insights. For example, the process by which I was able to secure interviews with certain senior government officials revealed much about the inner workings of bureaucracies in Canada. In addition to tape recording and then transcribing most interviews, I also noted such things as posture, tone of voice, and gestures during the interviews. On a few occasions, interview subjects drew diagrams to illustrate their points, which I collected. They often referred to documents, which I reviewed subsequently if I had not already done so. Thus, my analysis does not hang on spoken words alone, but on the interplay of transcription, inscription and description, thick as I could make it.

I was granted an interview with every diabetes health professional or researcher whom I approached. My requests to bureaucrats and senior advisors for interviews and information tended to "bounce around," yet also yielded an

interview each time I asked for one, although not always with the person whom I initially contacted. On a couple of occasions, the referrals were lateral; twice I was referred to a more senior person; twice a more junior person handled my request for information. In fact, identifying the “appropriate person” within governments often took considerable leg-work (read email messages and telephone calls). Responses to email requests for information were often rich, especially if I had made previous contact via telephone or in person, and always prompt.

Unlike many journalists, I could promise confidentiality and I believe that aided considerably in securing these interviews. That I could describe my project as an investigation into the linkages between biomedical science and health policy may have helped. Such linkages seem too weak in the eyes of many researchers and some highly-placed government officials. I also attribute the ease with which I could lay hands on internal government documents partly to Canada’s liberal access-to-information legislation. Political parties, journalists, and citizens routinely file access-to-information requests with governments, which has reinforced the obligation to provide such information and perhaps led to a willingness to accede promptly to “reasonable” demands.

The fact that I share my last name with the current Minister of Health, Allan Rock, surely eased the way. During the course of fieldwork, government officials, researchers, and representatives of lobby groups asked me outright 10 times whether I am related to Allan Rock. For example, at the close of a telephone conversation to set up an interview, one government official asked again for my name. After I said, “Melanie Rock,” she asked, “No relation?” I replied, “No relation,” and said that she was not the first to ask. Laughing, she said that otherwise, they could really lay down the red carpet. Such dialogues underscored the political processes that enfolded, and were the object of, my research.

In addition to studying conference presentations, analyzing speeches, and conducting interviews, I observed physicians and researchers as they taught medical students and upper-year undergraduates. I attended three lectures to

medical students (on diabetes, clinical practice guidelines, and public health, respectively), and I attended lectures in an undergraduate human genetics survey course, team-taught by five researchers. I also collected the assigned readings and lecture notes for this course. A tour of a laboratory aided my understanding of human genetics research.

As part of my fieldwork, I observed two workshops for diagnosed diabetics to round out my understanding of how physicians and allied health professionals presented knowledge about diabetes and how to control it. These events also provided me with an opportunity to observe how the adults and adolescents with diabetes responded to the information provided and to the opportunity to meet hitherto strangers with “the same” disease. These workshops only take place every couple of months, and so I had to gain permission to attend several months in advance. Seven months into fieldwork, I attended a two-day workshop for adolescents and then two months later, I attended a counterpart one-day event for adults.

By this time, the connection between diabetes and organ transplants had been underscored in several interviews and documents. Many people with diabetes end up losing kidney function, and so require dialysis to stay alive unless they receive a kidney transplant. As well, people with type 1 diabetes may be considered candidates for pancreas transplants, and more recently, for transplants of the insulin-producing cells only. To better understand how transplant medicine construes needs, values, and obligations in relation to diabetes, I observed three staff meetings of a transplant team. Each meeting lasted about an hour and a half.

In addition, I negotiated clearance to profile a participatory research and community intervention project, the Kahnawake Schools Diabetes Prevention Project (KSDPP), in an Indigenous community near Montreal. In the body of the thesis, I will provide more details about this project and the agreement permitting me to profile its history.

## CODA

Professionals whose work concerns diabetes tend to communicate via telephone and text (email, web sites, reports, scientific journals), punctuated by face-to-face meetings. My field research followed suit. I made extensive use of taped scientific presentations available for purchase; the number of people in Canada who wish to listen *post hoc* to conference presentations on diabetes is sufficiently large that it forms a “niche market.”

The circles of professionals that have played substantial roles in generating and circulating information about diabetes tend to be closed, but they are also fragmented. This research project did not rely on any one of these circles as a base – a “site” to be penetrated thoroughly, explained from the inside out, and put into context. In this sense, this thesis does not present an ethnography of *an* institution, a social-*qua*-physical space bound by time lines and through relations of power (Abélès 1995). Instead, I sought to understand the intersection of various professional circles or “fellowships of discourse” (after Foucault 1971 {1970}). To do this, I traced statements about diabetes across time and space, and across institutional boundaries.

This strategy was viable and productive largely because in concert, various contemporary institutions help constitute a peculiar space, the “the public domain,” which is demarcated from “private” conversations, musings, and happenings. Since it not exclusive to any particular site nor the preserve of any one group, “the public domain” is fragmented, yet amenable to consolidation through procedures that favour the production, preservation and transmission of rhetoric in “the public record.”

Practical as well as theoretical concerns led me to regard “increased recognition for diabetes in contemporary Canada” as a case study whose very formulation as such merits explanation. While I was shaping my doctoral research plans, I identified a few phenomena suggesting that diabetes had gained recognition. Upon taking an interest in diabetes, I also noted with care how diabetes caught my attention, and used these provocations to consciousness as

pulleys in the conduct of fieldwork. I rendered the means by which I decided to focus my doctoral project on diabetes into lines of inquiry that led back and forth in time and across geographical space. These inquiries lend texture to the point of departure and exit in an ethnographic project that aims to historicize and localize the present (following Burchell 1993; Foucault 1984 {1971}).

### **3. “A Stitch in Time Saves Nine”: Measuring the Sweetness of Blood**

Today, the diagnosis of diabetes hinges upon measuring the amount of glucose in a sample of blood, but for hundreds of years in “the West,” the diagnosis depended upon the detection of sweetness in the urine. A simple taste would confirm the diagnosis of diabetes mellitus. In the nineteenth century, the first chemical tests were developed to measure the amount of glucose in the urine. By the early twentieth century, these tests were routinely performed in hospitals and as part of life insurance examinations (Bliss 1982, 20-22). Blood glucose testing also became possible in the late 1800s, and underwent a series of refinements over the course of the 1900s.

Blood glucose testing offers greater precision than testing the urine. Blood glucose testing is also advantageous for preventing diabetic “complications” such as kidney disease. When the body’s cells do not absorb the sugar in the bloodstream, the task of filtering sugar out of the blood eventually falls to the kidneys. Sweet urine is a sure sign that the kidneys are struggling, but the absence of glucose in the urine does not necessarily mean that blood glucose levels fall in the normal range.

While the diagnosis of diabetes no longer depends on testing the urine, I learned during the course of fieldwork that urine glucose testing has not completely disappeared in practice. At a day-long workshop for adults with diabetes, one participant’s face and voice registered surprised embarrassment when told that urine testing was no longer recommended. She has a blood glucose meter, which she had brought with her to the workshop, but implied that she occasionally uses a urine strip as a convenient alternative to blood glucose testing. My research on how private commerce has increased recognition of diabetes in Canada underlines the continued popularity of urine glucose testing and the perceived advantages of blood glucose testing. As part of this research (see Chapter 8), I reviewed copies of a newsletter entitled “Diabetes and the

Pharmacist,” distributed to all Shopper’s Drug Mart franchises, which is Canada’s largest pharmacy chain. The September 1999 edition included the following bulletin, sparked by the tallying and analyzing of purchase patterns from across the country:

Did you know that the #5 test strip sold at Shopper’s Drug Mart . . . is a urine glucose test strip? In the age where blood glucose testing has been called the greatest discovery in diabetes care since the discovery of insulin, you can understand why urine glucose testing is so antiquated. Urine glucose testing provides the patient only a range by which to interpret the glucose reading; blood glucose testing delivers an absolute number. . . . The next time a customer comes to you to purchase urine glucose tests, spend a few minutes telling them the advantages of blood glucose testing and how you will train them, step by step, to use the latest technology.

This bulletin also underlines that, unlike urine glucose testing, unlike blood glucose testing, can only roughly indicate future health prospects because it provides only a “low” or “high” signal.

As these examples illustrate, blood glucose testing is required to diagnose diabetes, but blood glucose testing is not reserved for the diagnosis of diabetes alone. Rather, people with diabetes and their clinicians should monitor blood sugar levels on an ongoing basis to extend their life expectancy and improve their “quality of life,” say health professionals who specialize in diabetes. These professionals also emphasize that early diagnosis of diabetes can extend and improve lives because the monitoring and treatment process can begin before “complications” set in. Thus, the measurement of blood sugar can identify imminent danger or confirm the source of discomfort, but it can also detect risks to health that lurk in the months and years ahead.

In this chapter, I examine the investment of widely-accepted social ideal, that of a long and healthy life, in the sweetness of blood. More specifically, I explore how the signs and symptoms of diabetes interface with lived experience,

and I chronicle discussions within biomedicine about how best to check for dangerously sweet blood. To theorize my ethnographic data, I revisit philosophical and anthropological insights about disease, and I show how biomedical knowledge about sickly sweet blood commodifies human lives and transfigures kinship.

### **THE NORMAL AND THE PATHOLOGICAL**

All human societies, past and present, have probably had a concept comparable to the “norm,” in that all societies develop ideals and standards to which members may aspire and by which members and events are judged. The methods of quantification developed over the past few hundred years in Europe introduced some novel dimensions to such ideals and standards (Daston 1988; Hacking 1990). Starting with statistics about births, deaths and marriages, “normal” became construed as a numerical range that could be specified, achieved, or improved upon. Consequently, a person or thing could represent “normalcy,” or could be “normalized.”

The appearance of the verb “to normalize” accompanied the “avalanche of printed numbers” that befell Europe between 1820 and 1840 (Hacking 1982). This historic event was essential to defining and managing populations in biomedicine and in nation states, Hacking contends. His argument draws upon Foucault’s insights about the powers vested in and emerging out of a new kind of collective body—populations, construed as ungainly entities in need of liberal governance—that emerged during this period in Europe (Foucault 1994 {1979}). At first, the normalcy was defined as the opposite of pathology in biomedicine (Canguilhem 1989 {1943,1966}), but soon it took on much wider currency. Almost anything and everything can be normal these days, Hacking observes.

The normal stands indifferently for what is typical, the unenthusiastic objective average, but it also stands for what has been, good health, and for what shall be, our chosen destiny.

That is why the benign and sterile-sounding word ‘normal’ has

become one of the most powerful ideological tools of the twentieth century. (Hacking 1990, 169)

Ever since the “avalanche of printed numbers,” people described as “abnormal” and “normal” embody the need for improvement. “Normalcy” represents an ideal, to which “abnormal people” should strive, yet “normalcy” is the bare minimum. Progress would seem to require the normalization of populations, one body at a time, thereby raising the average and the standard.

Life expectancy at birth has become a global social norm, a crucial development for the valorization of longevity and quality of life analyzed in this thesis. People the world over likely prefer a long, healthy lives for themselves and their kin, yet the capacity to render individual lives and collective bodies as commensurable things whose “quality” differs dates back only about 150 years. The measurement of life expectancy and other “qualities” establishes benchmarks in ranking individuals, populations and governments. As will be shown later in this chapter, measuring blood sugar to diagnose diabetes indicates current and future “quality” of human lives.

Today, in addition to such things as age at death and the “quality” of a person’s lived experience, the word “normal” can reference genes. The diagnosis of disease typically precedes the detection of a genetic “defect.” That is, the identification of undesirable genes hinges upon framing lower “quality of life” and the prospect of a “premature death” in biomedical terms. As discussed further in Chapter 5, certain genotypes put one at increased risk for diabetes, yet genes do not figure in the definition of diabetes as a disease.

The interplay between sickly sweet blood and genetic make-up frequently surfaced in the human genetics course that I attended as part my fieldwork. In a hand-out explaining to the students how to detect if a given trait or disease is “genetically complex”, one of the instructors stated that, first, observation will reveal that the trait or disease “runs in families” yet not “in a straightforward Mendelian fashion.” To rule out “cultural factors” or infections, which also “run in families,” the researcher should examine the distribution of the trait or disease

in close relatives. “Another clue indicating complex inheritance is that the trait or diagnostic index is ‘normally’ or continuously distributed in the human population.” The geneticist elaborated on the second point by asking rhetorically, “What does a normal distribution mean?” and then recited:

The formal definition is 90% of the variance falls within one standard deviation of the mean, 95% falls within two standard deviations and 98% falls within three standard deviations of the mean.

The following statement then qualified this definition:

In practice, we also consider those variables possessed by everybody to be continuously (if not normally) distributed. This would include height, weight, IQ, blood glucose levels, blood pressure, etc. When we actually examine the distribution, for example of blood glucose, we find that the distribution is not truly Gaussian [normal], but skewed Gaussian. Above a particular cut-off point, the disease is diagnosed. For diabetes, the cut-off point has physiological relevance and thus is not purely arbitrary. For some other diseases, we are not able to draw the line so clearly.

As illustrated here, genetic understandings of diabetes invoke blood glucose levels to define the pathology, and by extension, normalcy. In other words, the locus of the pathology, diabetes, lies not in “defective” genes but in “deviant” bodies. From this perspective, some genotypes and some environments impose greater susceptibility to diabetes than others do.

### **EXPERIENCING AND IDENTIFYING DIABETES**

The “classic” signs of diabetes mellitus include frequent urination, constant thirst, unrelenting hunger, wasting, fatigue and weakness. These symptoms are not specific to diabetes, they do not always occur, and they do not follow a set sequence. As the body undergoes a transition to consistently sweetened blood, adaptation may occur, in which case the “classic symptoms” may be experienced as “normal.” Consequently, sweet blood can escape

awareness. Diagnosis sets the stage for interpreting the “classic symptoms” of sweet blood as signs that the future bodes ill.

### *Embodying Symptoms, Interpreting Signs*

In the workshops for adults and adolescents with diabetes that I attended, the timing and events surrounding diagnosis were popular topics. One woman told me that she has suffered from migraines for some time, and then she started noticing a new type of headache, accompanied by sweating. Menopause? she wondered. She was thirsty too. Finally she went to her doctor, who ordered a diabetes test. At the workshop for adolescents, a 16-year-old boy reported that the diagnosis has mainly brought relief. Now I can “get back to my normal life,” he said. Then he described playing in a hockey tournament just before he was diagnosed. His performance was poor, and he just didn’t know what was happening to him. In retrospect, he realized that his diabetes, not the physical exercise, had caused the intense fatigue and lack of mental concentration experienced that day. Thus, after the diagnosis of diabetes, the “classic symptoms” of diabetes become framed as part of living with diabetes. They become signs of sweet blood, of hyperglycemia.

Diabetes medications, especially insulin, can induce another dangerous bodily state: hypoglycemia. Hypoglycemia occurs when hardly any glucose remains in the blood. Typically, hypoglycemia results when insulin or oral agents, in combination with bodily maintenance and physical activity, evacuate almost all the glucose from the bloodstream. Particularly among people with type 1 diabetes, because they all require daily insulin injections to survive, hypoglycemia is an ever-present danger. Untreated, hypoglycemia can lead to delirium, coma and death. Over time, people with diabetes may lose awareness of the symptoms of hypoglycemia, underscoring the need for vigilance. One participant in the workshop for adults noted that some signs apply to both hyperglycemia and hypoglycemia. A diabetes educator confirmed her observation, and said that this is another reason “to test your sugars.”

A fact sheet prepared for distribution to Shopper's Drug Mart customers explains that "hypoglycemia results can result from not enough food, or delayed food; too much insulin or diabetes pills; or extra activity or exercise." The fact sheet includes a diagram reminiscent of a thermometer that indicates when blood glucose levels are "too high" or "too low." In between lies the normal range, captioned as "feeling great" (see Figure 4).

At the workshops for adolescents and adults with diabetes that I attended, the staff prompted the participants to recall the symptoms of, and blood glucose readings corresponding to, hypoglycemia and hyperglycemia. At the workshop for adolescents, a girl was instructed to write "Hypo" and "Hyper" at the top of a chalkboard. Then she recorded the signs generated by the group for each category. For "Hypo," the group came up with: blurry vision, fainting, shaking, dizzy, weak, moody. Under "Hyper", the group came up with lazy (which a diabetes educator qualified as "lethargic"), thirsty, frequent urination, dry mouth, moody, lack of concentration. In concluding this exercise, a diabetes educator commented, "You got most of them." To which one participant retorted, "What do you mean, 'most of them'? You know what you feel." Meanwhile, the diabetes educator added "feeling hungry" under "Hypo." Under "Hyper," she added "stomach-aches" and "headaches." The member of the group most recently diagnosed, only a couple of months previously, said that he certainly remembered the headaches and stomach-aches. Later, one of the adolescents commented about the difference between being high and being low: "When you're low, you can do something about it. But when you're high, you have to live with it."

### *Revisiting kinship*

Once diagnosed, people with diabetes occupy a different social space than previously. The diagnosed person may now seem more like certain members of their immediate or extended families in that they, too, have diabetes. Diagnosis may also renew connections with deceased relatives who had diabetes. The diagnosis of diabetes can also extend kinship by classifying individuals as

Figure 4:

## Treatment of hypoglycemia



# Treatment of Hypoglycaemia

People with diabetes, who are taking insulin\* or diabetes pills, may occasionally experience low blood glucose levels (hypoglycaemia). People who manage their diabetes with exercise and meal planning only are not at risk for hypoglycaemia. Hypoglycaemia is any blood glucose level that is lower than your acceptable range. It is important to know how to prevent hypoglycaemia, and how to recognize and treat it.

*You should always carry with you a fast-acting sugar to treat hypoglycaemia such as glucose tablets or glucose gel.*

**Hypoglycaemia is caused by:**

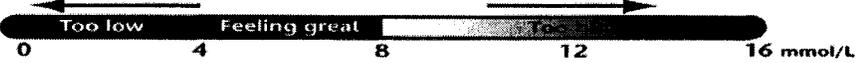
- not enough food, or delayed food;
- too much insulin or diabetes pills; or
- extra activity or exercise.

Take note of how often you are experiencing low blood glucose levels. If they are happening frequently — two or three times per week — you may need your doctor to adjust your diabetes medication or management plan.

\*Note: Hypoglycemia unawareness sometimes occurs in people with Type1 diabetes. That means common hypoglycemic symptoms are absent, even though blood glucose levels are too low. Check blood glucose levels more frequently, especially when operating a motorized vehicle. Carry Glucagon & ensure people close to you know how to use Glucagon.

**When you have low blood glucose you may have some of the following signs:**

- shaky	- hungry	- confused	- blurred vision
- dizzy	- emotional	- headache	- cannot concentrate
- tired	- nervous	- nausea	- increased heart rate
- sweaty	- irritable	- slurred speech	

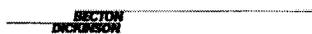


**What to do:**

<p>1. As soon as you know you are having a hypoglycaemic reaction — if you recognized your symptoms or if your blood glucose level is less than 4.0 mmol/L — take a <b>fast-acting sugar</b>. Always treat the symptoms, even if you are unable to monitor your blood glucose level.</p>	<p>2. If you have low blood glucose levels, take one of the following:</p> <ul style="list-style-type: none"> <li>• 1/2 cup of juice</li> <li>• 2 sugar cubes</li> <li>• 3 glucose tablets **</li> <li>• 1/3 cup of regular pop</li> <li>• 6 jelly beans</li> <li>• glucose gel **</li> </ul>	<p>3. Wait 10 to 15 minutes. Repeat the treatment if your symptoms persist or if your blood glucose level is still below 4.0 mmol/L. If your next meal is more than an hour away, eat a starch &amp; protein choice (e.g. cheese &amp; crackers) to ensure the blood glucose level will stay up until the next meal or snack.</p>
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\*\* Note: These are the only recommended treatments of hypoglycaemia for patients taking acarbose in combination with sulfonylurea or insulin.

This is a general guideline for the treatment of hypoglycaemia. Discuss treatment of hypoglycaemia with your diabetes care team to plan individualized diabetes care.



members of a very large group of people who are predisposed to consistently high blood sugars and attendant health risks. Thus, the measurement of blood sugar can establish “blood relations” with strangers and acquaintances. If “blood is thicker than water,” perhaps the measurement of the sweetness of blood to diagnose diabetes can lead to a kind of “clotting,” such that kith thicken into kin.

Health professionals advise diagnosed diabetics to monitor their blood sugars, to take prescribed medications and to count carbohydrates. This advice, the research upon which it is based, and the purchase and use of products to monitor and control blood glucose further agglutinate people with diabetes. Clinical trials, which follow hundreds and even thousands of people over several years to test pharmaceutical products and treatment regimes, figure especially prominently in reconfiguring kinship with blood relatives and with strangers *vis à vis* the diagnosis of diabetes.

The diagnosis of diabetes marks people as having abnormal bodies, even if they do not feel ill. Indeed, the frequent inability to recognize elevated or dangerously low blood sugar is a problem that regular blood glucose testing seeks to contain. Especially in the information geared towards adults, the capacity of consistently elevated blood sugars to increase, silently but surely, the risk for such chronic conditions as cardiovascular disease, kidney failure, amputations and blindness receives emphasis. By referring to cardiovascular disease, the leading cause of mortality in Canada and most other “developed” countries, the staff underlined that diabetes can shorten lives.

When dealing with children, more emphasis attends available measures to recognize and prevent the immediate experience of hyperglycemia and hypoglycemia. But tight blood sugar control and “complications” may be perceived as things to worry about in the future. When a diabetes educator circulated a “thermometer” for blood glucose similar to the one shown in Figure 4, one boy proclaimed, “I’m in the red, I’m going to die.” “But that’s for adults,” the diabetes educator replied in an effort to reassure him. “Being 12 or 13 over a long time, will you end up with complications?” another boy asked. The chances

of having complications increase, a diabetes educator affirmed. Her reply prompted another question: “By how much is it increased?” The diabetes educator replied that it is not easy to say, but on average, for every 1% reduction of hemoglobin A<sub>1C</sub>, the chances of complications reduce by about 15%.

Hemoglobin A<sub>1C</sub>, also known as “glycated hemoglobin,” indexes the average blood glucose level over the previous two to four months (Sinding 1999 provides a historical account of this clinical application). The adolescents who attended this workshop have their hemoglobin A<sub>1C</sub> levels tested approximately every three months. The ratio of hemoglobin A<sub>1C</sub> levels to long-term health prospects cited by the diabetes educator comes from a clinical trial (Diabetes Control and Complications Trial Research Group 1993).

This statistic was also presented at the workshop for adults that I attended. In fact, the endocrinologist had a bar graph from a DCCT publication copied onto an overhead transparency, which he presented and explained to the group. He said that the DCCT “proved absolutely conclusively that if you keep your blood sugar under control,” there is a drop in retinopathy [eye damage], nephropathy [kidney damage], and neuropathy [nerve damage]. The reason that the DCCT showed less of a decrease in neuropathy is that “there’s something genetic there” that can offer protection, he added.

At the diabetes workshops for adults and for adolescents, I observed that links drawn between sweet blood and such “complications” as heart disease and renal failure in clinical trials may inform “kin reckoning” in immediate families, while also extending kinship to encompass strangers and acquaintances. After being diagnosed with diabetes, the woman who wondered if the development of pounding headaches and sweatiness signalled menopause identified in a new way with her mother and with one of her brothers. Her mother had diabetes, and ended up with renal failure and amputation before she died. One of her brothers has diabetes, and he recently underwent bypass surgery. She spoke about “diabetes in the family” as we hovered in the hallway during a scheduled break. After we returned to the room where the workshop was being held, we continued to chat

until the workshop formally resumed. She told me that the hardest adjustment brought about by the diagnosis has been “watching my sugar,” and added that she used to work in a school cafeteria, so she really knows how to make desserts. Upon hearing this, another woman enrolled in the workshop nodded knowingly and became part of the conversation. Likeness was established by the common experience of monitoring sugar intake, and suppressing knowledge about how to prepare sweets. Later in the day, when a dietician explained that a certain artificial sweetener could be used in baked goods, and when she provided a couple of recipes for sweet-tasting but low-sugar desserts, notebooks came out of purses and pens flew. The hunger for this information registered a common cause: eating sweets without raising blood sugar levels.

The staff who conducted the workshop sessions actively encouraged those enrolled to develop kinship ties, even if apparently superficial ones. Both workshops opened with a presentation by an endocrinologist, and both endocrinologists stressed similarities among the participants. For example, at the workshop for adults with diabetes, an endocrinologist stated that the participants are the real experts on diabetes, because they live with the condition. Thus, the participants were represented as akin to one another because they all know viscerally what sweet blood feels like, unlike him. Then the endocrinologist asked how many in the group have a relative with diabetes. All raised a hand. Next he asked how many in the group were diagnosed with diabetes after the age of 40. All participants raised a hand, with one exception; she reported being diagnosed at age 19.

A pediatric endocrinologist kicked off the workshop for adolescents by asking each of the participants to report how old they were, how long they have had diabetes and how many “shots” [insulin injections] they take per day. These opening questions highlighted similarities among the participants, and also some differences. Over the course of the two days, as part of the formal program and informally, the adolescents named relatives with type 1 and type 2 diabetes. For example, one girl told the group that her uncle had stayed home from work

because he felt sick, slipped into a coma and later died. He didn't know he was a diabetic, she reported.

As alluded to in the preceding paragraph, the workshops sometimes referenced a genetic predisposition to sweet blood as something that the assembled shared. Yet in the workshop for adolescents, the staff underlined that type 1 diabetes is not inherited in a Mendelian fashion. Late in the first day of the workshop for adolescents, one girl expressed concern about having children in the future because she did not want to pass her diabetes on to another generation. A diabetes educator quickly leapt to the blackboard to note (correctly, see Barzilai and Shamoon 1997) the probabilities of type 1 diabetics having a child who would develop this condition: 5-9% for men with type 1 diabetes, 1-4% for women with type 1 diabetes and 20% if both parents have type 1 diabetes.

Overall, the ties developed during the course of the workshop for adolescents seemed more intense, reflecting the social position of the participants and the longer duration of their diabetes education program (two days for the adolescents, compare with one day for the adults). Indeed, staff told me that decreasing social isolation was one of the main goals of the workshop. Before the workshop proper began, three of the girls exchanged email addresses and swapped stories about having diabetes. "If there's another diabetic at my school, I don't know who the person is," one said. A couple of minutes later, she described being observed while injecting her insulin:

I was putting a needle into my leg and he was like, 'How can you do that in public?'

I was like, 'What?'

'I thought you were doing heroin.'

She inferred that diabetics who need insulin, adolescents with type 1 diabetes in particular, risk having a stigmatizing category mistake – illegal drug use – applied to them.

Both workshops scheduled times for testing blood sugar. For the adolescents in particular, collectively "doing a pick" [testing their blood sugars] provided an occasion to identify with one another by comparing equipment and

“numbers” [test results]. For example, one of the adolescents asked a fellow participant who tested at 2.1, “You were at 2? How can you let yourself go like that?” She grinned and said, “Don’t feel it.” At a scheduled “pick” just before lunch, one of the boys predicted that he would test “normal.” Another participant asked, “What’s normal?” Between 4 and 8, he replied. In fact, he tested at 11.9 mmol/L. As detailed later in this chapter, 7 millimols of glucose per litre of blood on an empty stomach is the threshold for diagnosing diabetes.

In invoking “kinship” to describe relationships between people who are members of the same nuclear or extended families, as well as affinities between people who are members of different families and even different ethnic origins, I am mindful of anthropological tradition – even if I risk stretching conventional, “Western” understandings of kinship beyond recognition. Through classic and more recent studies (Strathern 1992b, for example), anthropologists have grappled with naming and other practices that configure kin relations around the world. They have also examined the social and economic implications of kinship.

Anthropologists recognize Henry Louis Morgan as the first to make significant progress in theorizing cross-cultural variation in kinship. He found that many peoples around the world use “classificatory” kinship terminology. For example, they may use the same word to refer to their mother and to their mother’s sister. By contrast, “descriptive” kinship systems focus on biological descent:

In descriptive systems there are different terms for father and mother, husband and wife, brother and sister, and son and daughter, and none of these terms is applied outside the nuclear family. Morgan argued that such systems mirror the reality of biological kinship, clearly marking the degrees of blood relationship. (Kuper 1988, 56)

Following Morgan’s lead, W.H.R. Rivers pioneered the genealogical method precisely because he found that in Melanesia, kinship categories did not correspond with lines of biological descent. Certain duties and privileges, Rivers found, were part and parcel of certain kinship bonds. Kinship could include and

exclude certain people as potential marriage partners, for example (Kuper 1988, 157). Malinowski subsequently observed that biological paternity among Trobrianders was not formally recognized. By contrast, he observed that the mother's brother was widely acknowledged as an important figure. A Trobriand man was bound by duty to his sister's son and heir, but by love to his biological son, Malinowski maintained (Malinowski 1929).

These studies all take as a starting point that kinship in "the West" is quintessentially "descriptive" because it concerns biological relatedness in nuclear and extended families. From my research into diabetes, I conclude that this assumption needs to be revisited. I have found that "biological relatedness" can take into account relationships in nuclear and extended families, but can also include bodily similarities between people not conventionally recognized as kin. The measurement of blood sugar provides a basis for establishing degrees of relatedness with strangers. Indeed, once they take on a measure of kinship with strangers, people diagnosed with diabetes may reconfigure their relatedness with members of their immediate or extended families. Thus, by ascribing membership in a kin group dispersed across vast geographical and temporal distances, the diagnosis of diabetes can also prompt a person with diabetes to reconsider relationships with biological relatives who are also members of the much larger group because they, too, developed sickly sweet blood.

Measuring and comparing the sweetness of blood in different bodies can thus reconfigure kinship – not least when genetic similarities are invoked as possible root causes for elevated blood sugar levels and the onset of particular "complications" of diabetes. Not everyone who meets the diagnostic criteria for diabetes has been diagnosed, underscoring a tenet in anthropology: kinship is ascribed; it is never "simply" biological.

### **"YOU NEED TO KNOW"**

Through a national public education campaign that ran in English and French throughout 1997, the Canadian Diabetes Association (CDA) sought to

increase the number of diagnosed cases of diabetes. “You need to know” was the theme of the campaign, which stressed that many people who have diabetes have not been diagnosed. In raising awareness about the “classic symptoms” and “risk factors” associated with diabetes, the campaign encouraged people “at risk” for diabetes and its “complications” to undergo the diagnostic test for diabetes. Below, I discuss what this campaign reveals about the significance of measuring the sweetness of blood to diagnose diabetes. In addition to the campaign materials themselves, the following analysis draws upon a campaign summary supplied by the advertising agency retained by the CDA.

Campaign components included three television commercials, two radio commercials, print advertisements (Figures 5 through 9), and mass transit advertisements (Figures 10 and 11). The advertising firm developed various sizes and shapes of print advertisements. The radio and television advertisements each lasted thirty seconds. In all cases, whether or not the advertisements appeared did not depend on the CDA purchasing advertising space or time. Broadcasters, magazines, newspapers, and transit companies were asked to carry campaign materials in lieu of paid advertising and instead of other public service announcements. In other words, the campaign reached the public through gifts of advertising time and space.

Transit companies posted campaign materials more than 4,000 times in 1997 and broadcasters across Canada carried the radio and television advertisements, sometimes during “prime time.” Prime time slots are usually very expensive because the number of viewers is at its peak. Magazine advertisements appeared in four magazines, three of which have national distribution networks. A number of newspapers also picked up the announcements, including the sole nationally circulated newspaper in Canada at the time (the *Globe and Mail*). In fact, this newspaper published a report on diabetes during the campaign. Monsanto, which manufactures a low-calorie alternative to sucrose called NutraSweet, sponsored a full-page advertisement in this report valued at close to \$13,000 Canadian.

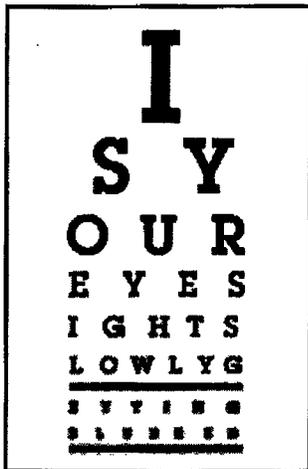
The “classic symptoms” of diabetes illustrated in this campaign were blurred vision, extreme thirst and frequent urination (see Figures 5 through 7). Weight gain, a family history of diabetes, and ageing were identified as other signs that “you could be at risk for diabetes” (see Figures 8 through 11). Rather than evoking sensory memories, the latter items call upon members of the public to identify themselves in relation to a certain type of body, particular ancestors, or living relatives, and a defined age set.

The print advertisement about weight gain features a line drawing of a pair of trousers and a belt (Figure 8). One can easily imagine a person straining to buckle this belt, which fit fine not so long ago. The caption reads, “Having trouble making ends meet?” This expression usually signifies financial troubles, but here the problem seems to be abundance, not a lack of resources.

Constant hunger is a “classic symptom” of diabetes, but weight gain is not. Rather, the “classic symptoms” of diabetes include rapid weight loss. Wasting results among people with diabetes when their bodies cannot utilize the energy consumed. Yet obesity, not rapid weight loss, is associated with type 2 diabetes. Thus, the line drawing of a belt that will not buckle refers to type 2, not type 1, diabetes because it references weight gain as a risk factor for the onset of type 2 diabetes.

“Checked your roots?” reads the caption of the print advertisement illustrating, by way of a pedigree, that a family history of diabetes can predispose a person to diabetes (see Figure 9). As alluded to above and as will be discussed in greater detail in Chapter 5, diabetes is a complex disease in genetic terms. It does tend to “run in families,” however, and this item asks the members of the public to reflect on their risk by remembering someone diagnosed with diabetes in their family. Since one in twenty people in Canada has been diagnosed with diabetes, many have at least one relative — alive or deceased — diagnosed with diabetes. In fact, “Help someone you know” is the theme of the current Canadian Diabetes Association public awareness campaign.

Figure 5:  
Blurry vision?



**BLURRY, VERY BLURRY?**  
**You could be at risk for diabetes.**

 CANADIAN DIABETES ASSOCIATION    ASSOCIATION CANADIENNE DU DIABETE

**YOU NEED TO KNOW.**

**CALL 1-800-BANTING**

**Figure 6:  
Thirsty?**



**THIRSTY, VERY THIRSTY?**

**You could be at risk for diabetes.**



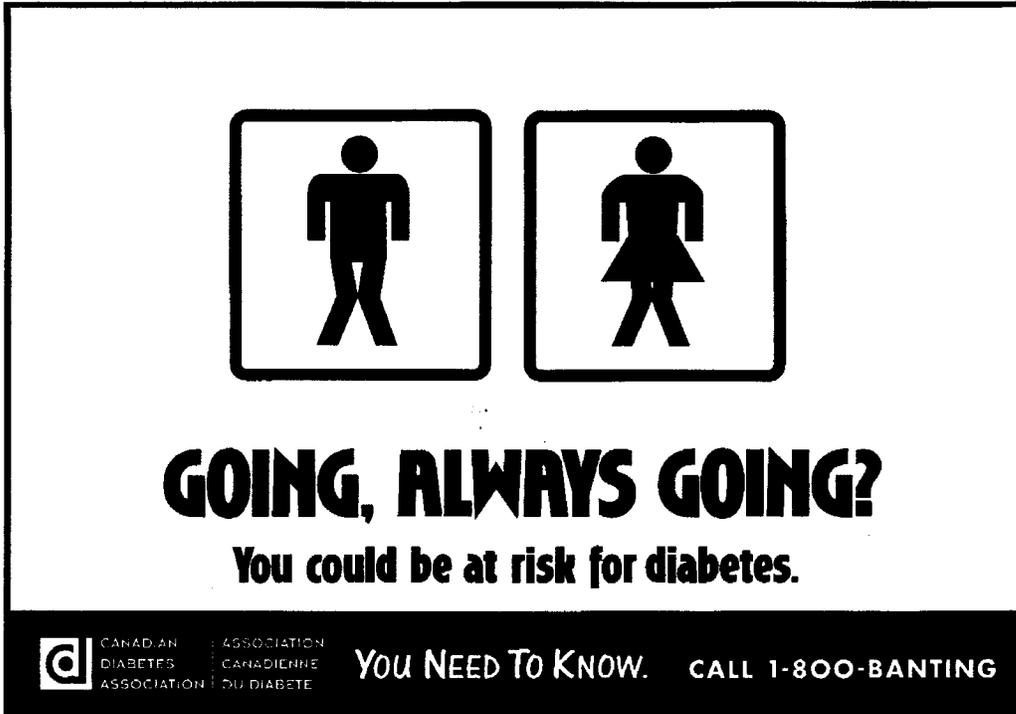
AMERICAN  
DIABETES  
ASSOCIATION

AMERICAN  
DIABETES  
ASSOCIATION

**YOU NEED TO KNOW.**

**CALL 1-800-BANTING**

**Figure 7:  
Always going?**



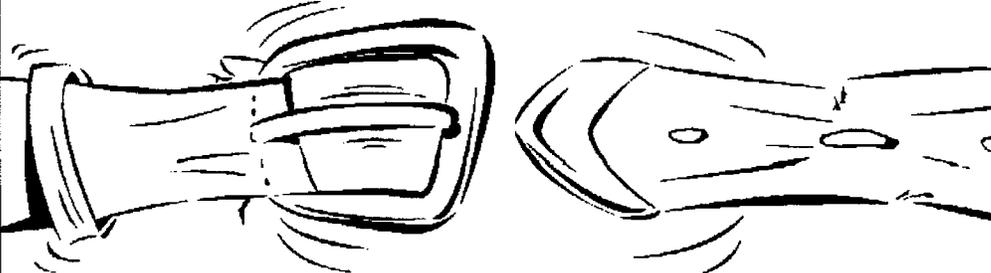
**GOING, ALWAYS GOING?**  
**You could be at risk for diabetes.**

 CANADIAN DIABETES ASSOCIATION / ASSOCIATION CANADIENNE DU DIABÈTE

**YOU NEED TO KNOW. CALL 1-800-BANTING**

**Figure 8:**

**Having trouble making ends meet?**



**HAVING TROUBLE  
MAKING ENDS MEET?**

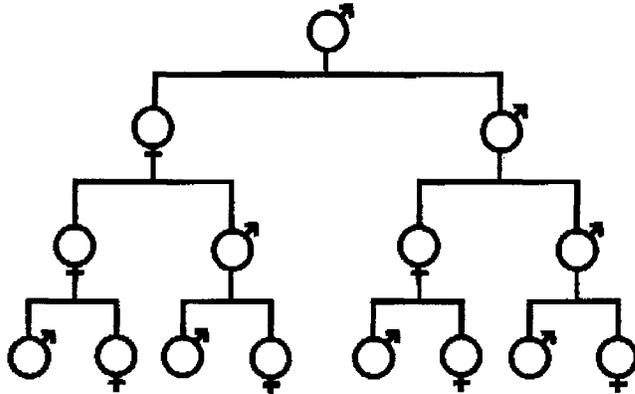
**You could be at risk for diabetes.**

 CANADIAN DIABETES ASSOCIATION    ASSOCIATION CANADIENNE DU DIABETE

**YOU NEED TO KNOW.**

**CALL 1-800-BANTING**

**Figure 9:  
Checked your roots?**



**CHECKED YOUR ROOTS?**

**You could be at risk for diabetes.**



CANADIAN  
DIABETES  
ASSOCIATION

ASSOCIATION  
CANADIENNE  
DU DIABETE

**YOU NEED TO KNOW.**

**CALL 1-800-BANTING**

Figure 10:

If you were at Woodstock...

**IF YOU WERE AT WOODSTOCK (OR SAY YOU WERE), YOU'RE AT RISK OF DEVELOPING DIABETES.**

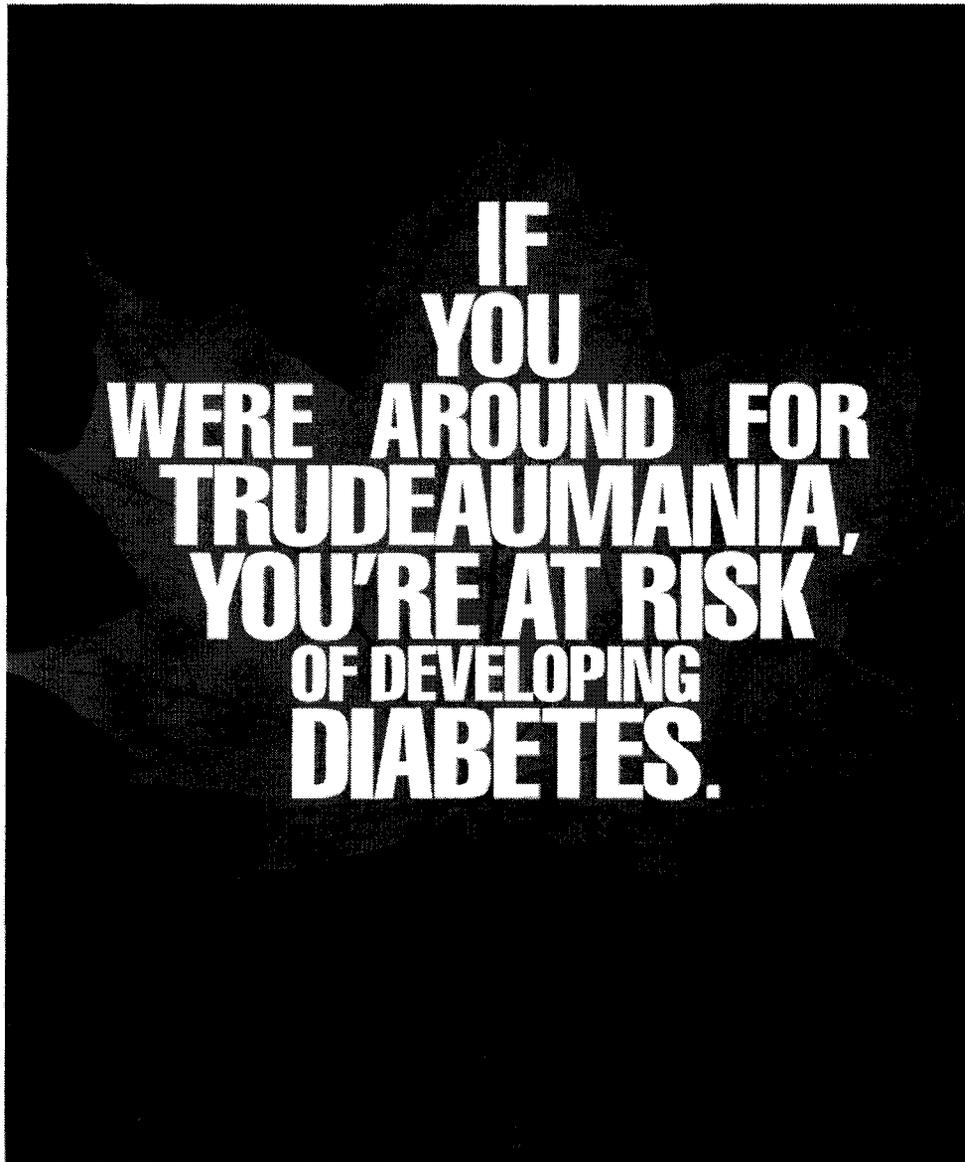
 CANADIAN DIABETES ASSOCIATION | ASSOCIATION CANADIENNE DU DIABÈTE

**YOU NEED TO KNOW.**

**CALL 1-800-BANTING**

**Figure 11:**

**If you were around for Trudeaumania...**



CANADIAN  
DIABETES  
ASSOCIATION

ASSOCIATION  
CANADIENNE  
DU DIABÈTE

***YOU NEED TO KNOW.***

**CALL 1-800-BANTING**

By asking members of the public to “check their roots,” this item also refers to ageing: dye will only cover grey hair for so long before the natural colour becomes visible near the scalp. In most of the 1997 campaign materials, references to the accoutrements of growing older were much more overt and focused on those born during the post-WWII baby boom. All three television spots, both radio spots and both transit advertisements signalled the significance of this age set. Indeed, the representative of the advertising company with whom I spoke called this the “over 45” public awareness campaign.

All three television spots stressed that diabetes is a much more serious than any concerns about reduced sexual appeal due to ageing. They featured, respectively, a man with a protruding belly in possession of a shiny red sports car, male pattern baldness, and female bodily sagging. At the close of these announcements, the narrator underlined that being over 45 increases the risk of developing diabetes, especially if the person is overweight, physically inactive or has a family history of diabetes.

The radio spots honed in on shared memories of baby-boomers to emphasize that after the age of 45, the risk of developing diabetes increases. One radio spot was termed “Happy Days.” After a few bars of a song by The Crew Cuts, an upbeat male voice chimed,

If you had a ducktail in your hair, fins on your cars, saddle shoes in your closet, Howdy-Doody on your lunchbox, James Dean on your bedroom wall, Beat poetry on your tongue, and doo-wop on your turntable, well [the tone of voice turned serious], there’s something you should have on your mind. You’re at risk of developing diabetes. Please, call the Canadian Diabetes Association at 1-800-BANTING for more info. Because you need to know, dig.

The other radio spot was termed “Hippie Days,” and was designed to resonate with baby-boomers’ memories of the late 1960s and early 1970s. Accompanied by snippets of The Byrds’ “Turn, turn, turn” whose lyrics allude to the rhythm of the seasons, it prompted listeners to recall psychedelic posters, go-go boots, false

eyelashes, sit-ins, love-ins, laugh-ins, hippies, yippies, bippies, pop art, and Art Linkletter.

One of the transit advertisements noted, “If you were at Woodstock (or say you were) you’re at risk for diabetes” (see Figure 10). The other alluded to a Canadian phenomenon, the so-called “Trudeaumania” that swept the country in 1968 (see Figure 11). Each transit advertisement included a paragraph explaining that after age 45, the risk of developing diabetes increases. I saw the Trudeaumania and Woodstock items several times over the course of fieldwork because they were made into 11x17-inch colour posters and distributed to diabetes professionals. I sighted these items posted at three out of four diabetes clinics where I conducted interviews and direct observations during 1999 and 2000. The diabetes clinic that did not have these posters up on its walls serves children and adolescents with diabetes, and therefore the campaign materials were not geared to its patients. I also saw very large, laminated copies of these posters — each at least five feet long and three feet wide, by my reckoning — hung on a wall at the headquarters of the Canadian Diabetes Association.

By emphasizing the “need to know” in the 1997 public awareness campaign, the CDA tried to encourage baby-boomers to undergo testing for diabetes, to modify their risk for type 2 diabetes by losing weight, and to regard the CDA as a highly credible source of information and support for diabetes. The CDA also sponsored the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada*, which were developed with support from six manufacturers of pharmaceutical products and medical devices. As documented below, the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* demonstrate concern for ensuring that testing occurs, while also ensuring that the test results are accurate.

### **A “PUBLIC HEALTH DISORDER” IN THE CLINIC**

The *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* begin by portraying diabetes as a “public health disorder” because it has

“a high disease burden, changing burden suggesting preventability, and fear that things are unknown and out of control.” (Meltzer et al. 1998, s2, citing; Vinicor 1994). To support this assertion, the document then marshals evidence concerning the current and projected prevalence of diabetes in Canada:

Currently the diagnosis of diabetes has been made in approximately 5% of Canadians or 1.5 million people. This number is expected to reach 2.2 million by the year 2000 and 3 million by 2010. Moreover, because United States statistics demonstrate that for every person with known diabetes there is someone with undiagnosed diabetes, these numbers most likely underestimate the prevalence of the disease. Assuming the same situation is true in Canada, up to 10% of all Canadian adults may currently have diabetes. (Meltzer et al. 1998, s2)

The “high disease burden” associated with diabetes is mainly due to the “complications” that can arise, which can impair its victims for many years and culminate in an earlier-than-average demise:

Diabetes is a serious health problem. It is a major cause of coronary artery disease (CAD), which is the leading cause of death in Canada. It is also a leading cause of new cases of blindness and kidney disease in Canada. The disease often disables people in their middle years and, as a group, people with diabetes die younger than those not affected by it. (Meltzer et al. 1998, s2)

Next, the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* refer to the financial impact of diabetes on the affected person and society as a whole (to be discussed in greater detail in later chapters). Overall, the introductory paragraphs of the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* aim to establish diabetes as a grave health condition that requires more systematic attention, especially from family physicians. The document argues that earlier diagnosis and more aggressive treatment of diabetes following diagnosis will result in improved health status while also reducing health care costs.

To promote earlier diagnosis, the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* recommended that the fasting plasma glucose (FPG) test become the “main diagnostic criterion.” As recently as 1994, the more cumbersome oral glucose tolerance test (OGTT) was the only internationally-recognized diagnostic test for diabetes (Canadian Diabetes Advisory Board 1994).

The OGTT, endorsed by the WHO in 1985, requires drawing a blood sample exactly two hours after swallowing 75 grams of glucose in liquid form. Patients must therefore spend more than two hours in the clinical setting to undergo this test, and to accord fully with the diagnostic criteria, a health professional must draw blood sample *precisely* two hours after the ingestion of the “glucose load.” The time commitment required from patients and clinical staff would tend to dissuade physicians from ordering this test for all but those at highest risk: it is not a “commonly available test” (Meltzer et al. 1998, s6). The FPG involves measuring the sweetness of the blood many hours (8 or more) after the last intake of calories. Compared to the OGTT, the FPG requires less time from patients and less time management from clinical staff.

To reiterate, reporting “classic symptoms” of diabetes is insufficient in making a diagnosis of diabetes. In all cases, a laboratory measurement of blood glucose must be obtained. In fact, after a positive blood sugar test result, a “confirmatory test must be done in all cases *in the absence of unequivocal hyperglycemia accompanied by acute metabolic decompensation.*” (Meltzer et al. 1998, s6, emphasis in original). The FPG is currently the clinical standard, but the OGTT is still performed.

Below, I detail recent changes to diagnostic and screening procedures spelled out in the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada*, beginning with life-long diabetes and then proceeding to gestational diabetes. In the section on life-long diabetes, I pay particular attention to why the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* endorsed a “new and improved” FPG test as the clinical standard over the

“gold standard,” the OGTT. In the section on gestational diabetes, I highlight the value accorded to measuring the sweetness of blood circulating in the bodies of almost all pregnant women, despite the lack of a “gold standard” for diagnosing gestational diabetes.

### **PRAGMATISM USURPS THE “GOLD STANDARD”**

Diabetes researchers often refer to the OGTT as “the gold standard” for diagnosing, and indeed, defining diabetes. Yet the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* currently recommend that physicians order FPG tests. Why this change? How did the “gold standard” become displaced? The FPG is more convenient than the OGTT for patient and physician alike, but the equivalency of the two measures was debated during the drafting of the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada*. The final document recommended lowering the FPG level required to diagnose diabetes and endorsed this re-tooled FPG as the clinical standard, if not the “gold standard,” for diagnosing diabetes.

#### ***The Value of Diagnosis***

The rationale provided for lowering the FPG diagnostic threshold for diabetes reflects the perceived value of the diagnosis itself. The *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* explain:

The lowering of the FPG diagnostic level from 7.8 to 7.0 mmol/L ensures that both the FPG and 2hPG [2-hour OGTT] define a similar degree of hyperglycemia and risk for microvascular disease. It also permits the diagnosis of diabetes to be made on the basis of a commonly available test — the FPG.  
(Meltzer et al. 1998, s6)

These two arguments given for lowering the FPG value necessary to diagnose diabetes both concern the perceived value of diagnosing as many people with sweet blood as possible. First, this change was made to increase the sensitivity of the FPG, when compared with the OGTT. Second, given the greater convenience

of the FPG compared with the OGTT, the authors of the 1998 CPG wanted to increase the numbers of people who would undergo testing, thus decreasing the number of undiagnosed cases of type 2 diabetes.

At 7.8 mmol/L, the previously recommended value for diagnosing diabetes using the FPG test, “a significant proportion of people in whom a diagnosis of diabetes would have been made based on glucose level 2 h after a 75-g glucose load never received this test and, thus the diagnosis was not made.” (Meltzer et al. 1998, 26). The failure to diagnose diabetes could result in the onset of “complications,” and even “premature” death. As spelled out in the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* and surrounding debates, knowing for certain whether or not one has type 2 diabetes is inherently desirable because the condition is amenable to control through “lifestyle modifications” and pharmaceutical products.

#### ***Evaluating diagnostic tests in terms of future “quality of life”***

In October 1998, just a few days before the official publication of the guidelines in the *Canadian Medical Association Journal*, Dr Sara Meltzer described the adoption of the FPG as the “primary diagnostic test” and “going to the value of 7” as “major changes.” She made these remarks at a plenary panel devoted to the new guidelines held during the 1998 CDA professional conference in Calgary, Alberta. Meltzer, an endocrinologist, co-chaired the steering committee charged with developing the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada*.

Dr Meltzer also stressed the urgency of diagnosing diabetes in an interview with the Canadian Broadcasting Corporation (CBC) the year before, in October 1997. The interview was woven into a story about the possibility of extending and ameliorating the lives of hundreds of thousands of people in Canada through earlier diagnosis of diabetes, which aired on the CBC’s nightly newscast (Mansbridge and Sherran 1997). When the anchor went through the headlines at the top of the newscast that night, diabetes received second billing.

First came a story about the quest to rescue 15 men lost in the North Atlantic Ocean off the coast of Newfoundland. The rescue operation provided a more dramatic story about saving lives than did earlier diagnosis of diabetes, even though diabetes afflicts at least 5% of Canada's population – sweet blood runs in the veins of one out of every twenty people in Canada, if not more.

The impetus for the diabetes story came from the draft clinical guidelines, tabled for comments at the 1997 Canadian Diabetes Association Professional Conference, held in London, Ontario. This plenary session, attended by some 1200 people, lasted over three hours, and over a third of that time was devoted to the recommended diagnostic criteria.

Several members of the audience questioned why the FPG value of 7.8 mmol/L had been equated with the OGTT value of 11.1 mmol/L in diagnosing diabetes. One audience member declared baldly, "You have arbitrary cut-off points for the fasting and the two-hours. The fasting blood glucose level is on a distribution curve, and it could be expressed as levels of probability in some manner..." His voice trailed off. These statements refer to the "normal" blood glucose levels distribution, and point to some challenges in defining a clinically-relevant threshold value that would apply to all human beings. The two tests referred to in this comment, the FPG and the OGTT, each results in a slightly different distribution curve when the results from a large sample are plotted on a graph. The OGTT, not the FPG, was used in the clinical trials and other studies that found the sweeter the blood, the more likely complications; and that even slightly elevated blood glucose levels, over the long term, could result in health problems. The question implied by this speaker is: On average, at what FPG value do the complications associated with high OGTT results begin to develop?

Dr Denis Daneman, an endocrinologist, chaired the Definition, Classification and Screening subcommittee and he fielded most of the questions about diagnosis. Here is how he responded to the observation, cited above that the FPG and OGTT tests have different distribution curves:

Well, I think that's a very important point. And Dr Lebovitz showed some of the evidence directly, that the different studies that have been done have suggested in milligrams per decilitre, anything from 117 to 130 [corresponds to the diagnostic threshold for diabetes using the OGTT], which is about 6.7 to 7.2 [mmol/L]. And the consensus agreement of the ADA (American Diabetes Association ) was to use the cut-off of 7 [mmol/L], which in all of those studies is consistent with the sharp inflexion increase in the risk of retinopathy. That's the choice of the 7.

By invoking an invited lecture delivered the previous day by an American endocrinologist, Dr Harold Lebovitz, Dr Daneman implied that “normal” and “pathological” blood sugar levels need to be defined by averaging their health effects in the human population as a whole. Further, he underscored that elevated risk for certain “complications” is integral to defining sickly sweet blood. In addition, his response reflected the view that definitions of diabetes ought not to change when crossing the Canada-US border. Nevertheless, as implied in this statement, a different measure of the sweetness of blood is standard in the United States than in Canada. In the United States, the sweetness of blood is usually computed as the ratio between the number of milligrams of glucose per decilitre of blood; in Canada, the sweetness of blood is calculated as the ratio between the number of millimols of glucose per litre of blood.

Dr Lebovitz was a member of the committee in charge of setting diagnostic criteria on behalf of the ADA, which circulated its preliminary conclusions while the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* were being developed (see Report of the Expert Committee on the Diagnosis and Classification of Diabetes Mellitus 1997). As signalled above, the American committee endorsed a FPG of 7.0 mmol/L (or 126 milligrams per decilitre) as the clinical standard for diagnosing diabetes, just like the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada*. The made-in-America recommendations, however, did not purport to be “evidence-based.” Rather, Dr Daneman reminded the assembled crowd at the

1997 CDA Professional Conference, they were “consensus-based.” A new set of clinical practice guidelines released in 2001 incorporated the diagnostic criteria adopted in 1997, with only a few changes concerning gestational diabetes (see Report of the Expert Committee on the Diagnosis and Classification of Diabetes Mellitus 2001).

That the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* are “evidence-based” is a source of pride for all those involved, judging from the interviews that I conducted, remarks made at the CDA professional conference presentations about them, and the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* themselves. In the final summary of the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada*, one can read, “These are the first evidence-based clinical practice guidelines in the Americas.” In 1997, Meltzer told the audience at the 1997 CDA Professional Conference, “[W]hen I was at the IDF [International Diabetes Federation Conference], the Australians—the Southern Australians—they’ve actually done evidence-based guidelines on diabetes. So we’re the second in the world.” Upon further analysis, however, the Australian CPGs did not meet the stringent “evidence-based” standards used in the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada*. So far, only Canadians have developed comprehensive clinical practice guidelines for diabetes derived from systematically reviewing and grading the available evidence (Harris and Webster-Bogart in press, 9).

The recommendation that the FPG become the clinical standard for diagnosing diabetes found favour with many general practitioners, such as the one who approached a microphone after the penultimate draft of the new guidelines were tabled at the 1998 CDA conference. He identified himself by name and as a family physician, and then stated, “I’m delighted to see the near demise of the glucose tolerance test. Can some of you tell me what, if any, are the indications to do it now?” Dr Lawrence Leiter, who co-chaired the steering committee with Dr

Meltzer, replied, “Basically we’re saying that primarily it should be reserved for research purposes.”

This inquiry about the utility of the OGTT followed on the heels of an intriguing dialogue, in which the power to definitively characterize diabetes remained with the venerable “gold standard,” the OGTT.

An endocrinologist, Dr Jean-Louis Chiasson, touched off this exchange by contending that the OGTT is still more sensitive than the 7.8 mmol/L FPG test. That is, Dr Chiasson claimed that even the improved FPG endorsed in the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* has a higher false-negative rate than the OGTT.

Two endocrinologists involved in developing the guidelines, Drs Leiter and Zinman, challenged Dr Chiasson to support his assertions. Dr Leiter, as mentioned in the previous paragraph, co-chaired the steering committee, while Dr Bernard Zinman co-chaired the complications subcommittee. Dr Zinman was one of the investigators in a landmark clinical trial, the DCCT, referred to earlier in this chapter, which established that tight blood glucose control significantly decreases the risk of “complications” among type 1 diabetics.

Then Dr Hertzler Gerstein, who chaired the “evidence-based” subcommittee, jumped into the debate to back Chiasson’s position. (Dr Meltzer had fondly identified Dr Gerstein as “our policeman” when introducing committee members to the crowd.) Dr Gerstein expanded on the public health rationale for recommending that the FPG become the clinical standard. Prior to earning a master’s degree in clinical epidemiology, Dr Gerstein completed fellowships in both internal medicine and endocrinology.

Dr. Chiasson started off:

I think that you have done a tremendous job. And I think that you need to be highly recommended and congratulated. Like you all said, things move very, very rapidly. Even as you write down those recommendations, things have changed, OK. And so I would like to make a few comments. And maybe a few suggestions for the updated next year’s issue.

The low-key delivery of the last line prompted laughter from many members of the audience.

My first comment is regarding diagnosis. I don't think there is any problem; I think that it is well described, and I think that the changes that have been brought forth are in accordance with the ADA recommendations. And I think that there are major reasons why these were changed. And I think that the 7-mmol fasting plasma glucose should, theoretically at least, increase the number of undiagnosed that would be diagnosed. However, I think it needs to be emphasized that the fasting plasma glucose will still miss over 50% of the undiagnosed type 2 diabetes. OK. And I think that's an important thing.

Dr. Leiter swiftly intervened, calling for Dr Chiasson to support his assertions with research: "OK, I'm sorry. Very provocative statement. Since these are evidence-based guidelines, we need evidence-based comments, so that—"

Dr. Chiasson indicated that he could meet this challenge: "Want me to quote, want me to quote that?" Dr Leiter affirmed; Dr Chiasson continued:

OK. I have two quotes, OK. One is our STOP-NIDDM trial where we have over 10,000 oral glucose tolerance tests. And in that, when you look at the fasting plasma glucose versus the golden standard, which is the 2-hour post-75-gram, over 50% will be missed. The second quote is from—

At this point, Dr. Zinman entered the debate. He wanted clarification: "Tell me, is that, is that *missed* impaired glucose tolerance [abnormally sweet blood, as measured by the OGTT, that is not sweet enough to diagnose diabetes], or *missed diabetes*?"

Dr Chiasson told him, "Missed diabetes, OK." Dr Zinman said, "I didn't think that, that other data (Dr Chiasson interposed, "Oh yes") sort of agreed with that." Dr. Chiasson continued to state his case:

The second quote, the second quote is data from Maureen Harris, OK. She has two sets of data. And she shows that if you look at the 7-mmol fasting plasma glucose, you missed exactly 52%,

OK. That's number one, OK. The other thing which I wanted to point out is that in this, in these [draft] guidelines, it states, and I quote, 'The fasting plasma glucose is the most reliable test for diagnosis.' And I don't think that's correct, OK. I think that the golden standard still remains the oral glucose tolerance test. And the, and as a matter of fact, the 7 mmol is highly specific [few false positives], but it is not very sensitive [frequent false negatives]. And again, the specificity is based on the oral glucose tolerance test. The—

Dr. Leiter interjected as chair to make way for a new participant: "Sorry. Before you, perhaps, Dr. Gerstein, do you want to [pause] respond?" This conjecture drew some tittering from the audience.

Dr. Gerstein had rushed to the microphone. He arrived out of breath but ready to weigh in on the debate:

Jean-Louis [Dr Chiasson] is 100% right. The sensitivity of a fasting plasma glucose of 7, when you compare it to the gold standard of an oral glucose tolerance test, is about 59%, or something. So, in fact, you're 100% right, it [an FPG of 7.0 mmol/L] is extremely specific. But a fasting plasma glucose of 7.0, if you don't do, if you compare it to the OGTT is not sensitive.

In confirming that a FPG test set at 7.0 mmol/L is less sensitive than an OGTT test set at 11.1 mmol/L, Dr Gerstein underscored that many people who would test positive for diabetes using the OGTT would test negative using the FPG.

Dr Gerstein reasserted the validity of Dr Chiasson's observations about the sensitivity of the FPG, and explained why the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* still endorse a FPG of 7.0 mmol/L as the standard diagnostic test:

So you're [Dr Chiasson] 100% right. The focus for that 7.0, and the focus on the fasting glucose is from a public health perspective. It's that many family physicians have patients in their office with fasting glucose levels of 9.0 and they diagnose

schizophrenia or borderline diabetes or some other psychological diagnosis, borderline, or whatever. And it's to really highlight the point that a glucose greater than 7 is diabetes. So, if you compare what people do in practice, we will pick up more patients with a 7, even though if you did a glucose tolerance test you'd miss—

Dr. Zinman interjected, “That’s very true.” Dr Zinman confirmed that pragmatic considerations have led the committee to recommend the FPG. Lowering the value necessary to diagnose diabetes using a FPG test to 7.0 mmol/L has increased the sensitivity of the FPG, but the OGTT remains “the gold standard” by which the FPG test is judged.

The public dialogue concerning the sensitivity and overall utility of the 7.0 mmol/L FPG test continued into the next day when Dr Chiasson delivered an invited lecture on the implications for clinical practice of the United Kingdom Prospective Diabetes Study (UKPDS). This 20-year study of over 5000 people with type 2 diabetes reported its final results only a few weeks before the 1998 CDA Professional Conference. Dr Chiasson said that the UKPDS supplies “three main lessons” for implementing the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada*. First, he observed that half of the UKPDS subjects already had one or more “complications” at diagnosis. This finding suggests that routine testing in a broader segment of the population could extend and ameliorate lives by diagnosing and treating type 2 diabetes earlier. Second, Dr Chiasson observed that the UKPDS showed that once type 2 diabetes sets in, no matter the treatment, there is a gradual and continual decline. Apparently, this decline is due to deterioration of the insulin-producing cells in the pancreas, a process that remains resistant to available treatments. Third and most importantly, said Dr Chiasson, the UKPDS showed conclusively that intensive blood glucose control decreases risk of complications among people with type 2 diabetes.

Dr Chiasson showed a slide comparing the DCCT and UKPDS results for the impact of tight glucose control on the incidence of macrovascular disease, microvascular disease, cerebrovascular disease and on mortality rates. He said,

“[Y]ou can see that the numbers are very similar” in that “just a 1% reduction in hemoglobin A<sub>1C</sub> will have a significant effect in the risk reduction of these complications.” Overall, Dr Chiasson found that the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* and the UKPDS agree quite well. He added:

The only comment that I would make, and it’s a comment that I made yesterday, and it’s the fact that if we use only the fasting plasma glucose for diagnosis that we miss a certain number of diabetics. And I put in this slide again for Bernie [Dr Zinman] just to — [much laughter from the audience] This is from Maureen Harris and it’s just to show that if you use the 7 mmol limit, that you miss 52% of the diabetics.

At the close of Dr Chiasson’s presentation, Dr Zinman approached the microphone:

Zinman, Toronto. Many of you may not realize, but Jean-Louis and I have a lot in common, and agree on most things.

This opener caused several panel members, including Chiasson, to giggle. Dr Zinman continued:

We were interns — there was such a thing as an intern back then, at the Montreal General — together. We get our hair styled at the same place.

This last remark garnered roars of laughter from the audience, and a chuckle from Chiasson. Having publicly established affinity with Dr Chiasson, Dr Zinman moved to his main point:

And most importantly, I’m sure that Jean-Louis does not want you to go away with the message that you should be doing a glucose tolerance test as a screen for diabetes. Correct?”

Dr Chiasson responded:

Yes, that’s correct. And I think that it’s good that you bring this up. But you didn’t have to mention my age at the same time.

Dr Zinman laughed, as did many members of the audience. Dr Chiasson continued:

But I'd like to make a comment on that, OK, and I think that's true. You don't want to go ahead and do an oral glucose tolerance test, you know. However, you have to realize that we are still leaving a population behind. I think that if you apply the diagnostic criteria as recommended by the CDA at the present time, you will increase the population that you will diagnose. That in itself — which is the population which is most likely to develop complications.

Dr Zinman says, "Right." Dr Zinman agreed with Dr Chiasson's assessment that, of those who would score 11.1 mmol/L or more on the OGTT, those who score 7.0 or more on the FPG are at highest risk for complications. Dr Chiasson, for his part, endorsed the adoption of the FPG as the clinical standard because it promises to increase the number of people tested, and ultimately treated, for diabetes. In his final remarks on this subject in this forum, Dr Chiasson suggested that prospective studies may find that some people with FPG scores lower than 7.0 mmol/L may be at risk for "complications", in which case, "we may modify the recommendations."

### ***Evaluating screening: Beneficial for whom?***

"Testing for [type 2] diabetes using a FPG test should be performed every 3 years in those over 45 years of age," advise the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* (Meltzer et al. 1998, s7-s8). Here we see a direct link between these guidelines and the CDA's "over 45" public awareness campaign. This recommendation did not meet with universal approval, because it allegedly fashions illness out of health.

In response to a summary of the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* published in the *Canadian Family Physician* (see Harris and Macaulay 1998), a letter to the editor opined:

I read the article that summarized the Canadian Diabetes Association's Evidence-Based Clinical Practice Guidelines with the scepticism that I usually bring to 'guidelines' prepared by

well-intentioned special-interest groups. I note that the association recommends screening for type 2 diabetes among those older than 45 years of age every 3 years with fasting plasma glucose levels. Further, I note that this recommendation is based on ‘consensus’ plus level 4 or weaker evidence. Presumably this is the same evidence that led the (more objective?) Canadian Task Force on the Periodic Health Examination to recommend that screening for diabetes be excluded from consideration in the periodic health examination. (Roedde 1999)

This letter asserted:

It is important to remember that these are well patients that that we want to make ‘sick,’ not ill patients we want to diagnose and treat. The onus is on those who advocate screening to prove that screening interventions (with all interventions that follow) does more good than harm and that the risks and benefits are quantifiable. (Roedde 1999)

Harris and Macaulay replied that recent studies suggest that “people with diabetes detected by screening are at higher risk for macrovascular disease and that earlier detection provides an opportunity to reduce the development of major complications and thus be cost-effective.” They also expressed the hope that “two large randomized multicentre trials currently underway” will be able to establish whether “selected diabetes screening can help prevent diabetes among those identified to be at high risk of developing diabetes (i.e., those with impaired glucose tolerance)” (Harris and Macaulay 1999). Contesting the letter writer’s assertion that people with undiagnosed type 2 diabetes are fundamentally healthy, they emphasize that by detecting sweet blood earlier rather than later, vigilant general practitioners can extend and ameliorate their patients’ lives.

Besides testing patients over the age of 45 for diabetes every three years, the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* recommend more frequent and/or earlier testing for people with first-degree relatives with diabetes; people of Aboriginal, Hispanic, Asian or African descent;

people who are obese; and people with a low level of high-density lipoprotein (HDL) cholesterol or high fasting triglyceride levels. In addition, the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* recommend annual testing for anyone with “predictive risk factors.” These include impaired glucose tolerance (abnormally sweet blood, as measured by the OGTT, that is not sweet enough to diagnose diabetes); impaired fasting glucose (abnormally sweet blood, as measured by the FPG, that is not sweet enough to diagnose diabetes); “complications” associated with diabetes; gestational diabetes (discussed below); hypertension; and coronary artery disease.

### *Accuracy and other values*

To round out my understanding of recent changes to diagnostic criteria and screening recommendations, I interviewed six of the committee members charged with developing the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada*. The value of a timely diagnosis has increased because the pharmaceutical armamentarium for diabetes and its “complications” is much more effective today than even a few years ago, these diabetologists stressed. In this way, better medications heft the value of the FPG test because physicians are more likely to order FPG tests and patients are more likely to follow through with the FPG than the OGTT. In addition, they stressed the UKPDS results, captioned above, that justify routine testing. One committee member described the latest version of the Canadian Task Force on the Periodic Health Examination, published in 1994, as “way out of date” as regards its recommendation *against* screening for type 2 diabetes among older members of the population. Another said that this discrepancy would need to be resolved in future, implying that the Canadian Task Force on the Periodic Health Examination should update its recommendations.

Concerning diagnosis, here is what one committee member said about the adoption of a 7.0 mmol/L fasting plasma glucose test as the clinical standard:

...the change in the criteria has been to simplify, for the vast majority of the population, knowing that people [general

practitioners] are not doing OGTTs. But the gold standard is still the OGTT. That's where we have our proofs that complications arise. Macrovascular complications, even micro, most of it was done with the OGTT. So that still is the gold standard. The reason that we're not suggesting that in the general population is just a question of reality. And it's probably the least evidence-based part of the guidelines, diagnosis. It's because we clearly wanted to go with the Americans. So the evidence suggests that it makes sense to do it that way, but it's certainly the one area that was most debated, and where it was the least solid in terms of evidence.

This summary of the issues facing the committee for the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* recalls Lorraine Daston's contention that accuracy is but one of the virtues of quantification. Accuracy, she points out, can be detached from such virtues as precision:

Accuracy concerns the fit of numbers of geometrical magnitudes to some part of the world and presupposes that a mathematical model can be anchored in measurement; precision concerns the clarity, distinctness, and intelligibility of concepts, and by itself, stipulates nothing about whether or how these concepts match the world. (Daston 1995, 8)

By promulgating the FPG test, the committee knowingly sacrificed a certain degree of accuracy and precision for commensurability, universality, and especially convenience. The committee was well aware of the discretionary powers of physicians to order tests, and of patients to submit to them. They sought to establish a diagnostic standard for diabetes whose demands on time could be kept to a minimum, so as to increase the number of tests actually performed, diagnoses made, and "complications" averted. Thus, the committee lowered the diagnostic threshold of the FPG to better the fit between the OGTT and the FPG, but this change did not increase clarity, distinctness or intelligibility in defining diabetes.

The OGTT remained “the gold standard,” the most precise and accurate way known for diagnosing diabetes. The OGTT is a precise test in that it carefully defines the amount of sugar to be absorbed in a bounded period of time. It is considered an accurate test because it produces evidence of abnormal blood sugar levels in the body of a particular person, and it also predicts the onset of microvascular and macrovascular disease. That is, unless measures are taken to lower the blood sugar levels, studies suggest patients diagnosed with the OGTT will likely develop the “complications” associated with diabetes. Further, those who meet the FPG of 7.0 mmol/L as well as the OGTT are at more risk for complications.

The convenience of the FPG seemed very attractive to those who drafted the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* and, in the United States, the *1997 Report of the Expert Committee on the Diagnosis and Classification of Diabetes Mellitus*. Mindful of how practical constraints inhibit broad clinical application of the more accurate and precise OGTT, the question became how to improve the accuracy of the FPG. By lowering the FPG value required to diagnose diabetes, these diabetologists sought to improve the equivalency of this more convenient test with the OGTT, and in this way, increase commensurability between the two tests. In other words, they sought to reproduce the OGTT’s ability to predict long-term health risks using the FPG.

While the Canadian committee was in the process of developing their “evidence-based” guidelines, American diabetes professionals determined that a FPG reading of 7.0 mmol/L accurately represents the health risks indexed by the OGTT result of 11.1 mmol/L (see Report of the Expert Committee on the Diagnosis and Classification of Diabetes Mellitus 1997). The Canadian committee was faced with the challenge of articulating an “evidence-base” for the American committee’s “consensus-based” recommendation, if they did not want to part company with their American counterparts. The *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* provide three references to

support the recommendation that the FPG level used to diagnose diabetes should be lowered to 7.0 mmol/L from 7.8 mmol/L: the American committee's report cited above, followed by two review articles comparing glycated hemoglobin, the OGTT and the FPG as diagnostic tests.

### **GESTATIONAL DIABETES: VALUING PRAGMATISM**

Gestational diabetes results when pregnant women develop elevated blood glucose levels, which often return to the normal range following childbirth. The pathology in gestational diabetes is partly established in reference to the fetal body and partly in reference to the pregnant woman. The diagnosis applies to the duration of a pregnancy, but it implicates the entire life span of both fetal and maternal bodies. Certain patterns of fetal development can mark mothers and infants alike as being at higher than normal risk for diabetes during the course of their lives, as well as at higher risk for pain and even trauma during childbirth. Once separated from a womb suffused with sweet blood, the newborn may experience dangerously low blood sugar levels.

The *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* explain:

GDM [gestational diabetes mellitus] occurs in 2% to 4% of all pregnancies, and the diagnosis of GDM has implications for both the baby and mother. The established morbidity for the baby includes macrosomia (with the risk of fetal and maternal trauma during birth) and neonatal hypoglycemia; other consequences are now rare. Although the value of diagnosing and treating GDM has been questioned, recent cost-benefit analyses have demonstrated the value of treating this condition primarily due to decreased costs for care of the newborn. The value of identifying a mother who is at high risk for later diabetes remains unproven; however, the incidence of postpartum diabetes mellitus, IGT [impaired glucose tolerance] and lipid abnormalities is elevated. (Meltzer et al. 1998, s7)

Hence, the diagnosis of gestational diabetes has immediate pragmatic value in that it may identify women among whom childbirth is likely to be “complicated” unless blood can be unsweetened. The diagnosis of gestational diabetes can also indicate women and children at higher risk for lifelong diabetes, suggesting more intense clinical surveillance and self-monitoring than might otherwise be warranted. In addition to increasing the risk of lifelong diabetes for the mother, children whose mothers had hyperglycemia during their early development *in utero* have an increased risk of childhood obesity and of developing type 2 diabetes by early adulthood (Meltzer et al. 1998, s19).

Not all physicians and policy-makers accept the value of this diagnosis, as illustrated above. The diagnostic criteria for gestational diabetes recommended in the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* – similar to the diagnostic criteria for life-long diabetes – exhibited concordance with medical science, but they also sought to have broad practical application in clinical settings. The authors put a premium on pragmatic utility.

“The worldwide diversity of criteria for the diagnosis of GDM [gestational diabetes mellitus] continues to be problematic,” according to the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada*. Gestational diabetes was first characterized in 1964 using a 100-g, 3-h oral glucose test: the sweetening of blood during pregnancy was found to index long-term risk of diabetes in the mother. Subsequently, the sweetening of blood during pregnancy was found to correlate with neonatal morbidity. In 1985, the WHO recommended that the standard OGTT (a 75-g, 2-h test) be used to diagnose gestational diabetes, but suggested treating pregnant women with impaired glucose tolerance. Nevertheless, the 100-g, 3-h OGTT remained “the gold standard” for diagnosing gestational diabetes (Naylor 1989). By 1998, this “gold standard” was no longer current, but neither had an alternative unequivocally taken its place. Hence, blood sugar measurement for the diagnosis of gestational diabetes falls short of some of the virtues of quantification: universality, accuracy and precision (Daston 1995). The *1998 Clinical Practice Guidelines for the*

*Management of Diabetes in Canada* still portray screening for gestational diabetes as worthwhile because the diagnosis promises to identify “high-risk” pregnancies and “at risk” patients, at least some of the time.

The “normal” range of blood glucose is narrower for pregnant women than for other people, whether measured using the standard FPG or OGTT. In addition to the standard FPG and OGTT, the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* endorse a one-hour OGTT as a possible diagnostic test. The authors regard the 75-gram, 2-hour OGTT as superior to what used to be “the gold standard” for diagnosing gestational diabetes, namely, a 100-gram, 3-hour OGTT. The 75-gram load entails “less nausea, less time for the patient and cost savings” over the 100-gram load. The *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* recommend that all pregnant women be screened for gestational diabetes between 24 and 28 weeks, except for “lean Caucasian women under age 25 years, with no personal or family history of diabetes and no history of large babies.” (Meltzer et al. 1998, s7) Figure 12 displays the numerical values for life-long and gestational diabetes endorsed by the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada*.

When draft guidelines were tabled at the 1997 CDA Professional Conference, an audience member questioned the rationale for the proposed gestational diabetes diagnostic criteria. In response, Dr Meltzer explained, “The problem is that the [100-g, 3-h] test is uncomfortable, it’s more complicated than a two hour test, it requires more of that gucky liquid that the poor pregnant lady has to take.” Then she recapitulated how the committee interpreted published studies and the vagaries of clinical practice:

[Dr Edmond Ryan’s] reasoning was basically if we go back to Sach’s data, which is normative data with a [1-hour] 75-gram [OGTT] on 3500 women, and you take two standard deviations of that, on a plasma glucose, it’s reasonable to assume that if you’ve got the same normative data from the same kind of population base; you’re likely to be diagnosing the same

## Figure 12:

### Diagnosing diabetes mellitus

	Fasting Plasma Glucose	Plasma Glucose 1h after 75-g Glucose Load	Plasma Glucose 2h after 75-g Glucose Load
Diabetes	$\geq 7.0$ mmol/L	N/A	$\geq 11.1$ mmol/L
Gestational Diabetes	$\geq 5.3$ mmol/L	$\geq 10.6$ mmol/L	$\geq 8.9$ mmol/L

(Adapted from Meltzer et al., 1998, s6)

grouping. And that's where the numbers of 10.6 [for a 1h, 75-gram OGTT] and 8.9 [for a 2-hour, 75-gram OGTT] come from. In fact, Sach's data is 10.7. Similar — not normative — data from Lind were 10.5. We're all used to 10.6, so that's why the number that's listed there is 10.6.

The number 5.3 does not go along with Sach's original data. In fact, it was 5.5, I believe, or 5.6. But this is the corrected data that Carpenter and Coustan's criteria have been using now for a number of years. It also happens to be *the* point in time or number that seems — It seems to be the number that influences outcomes in terms of macrosomia, which is the major problem we seem to still have with gestational diabetes. So the number has been put at the nominal value of 5.3, rather than 5.5. Again, there are a number of normative data for that fasting spot, and they vary a lot — not a lot, but a little. So that's where that number comes from. So that's the philosophy behind it. We hope, we hope it will be adopted because it's a much simpler test.

In the final version of the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada*, two studies “involving over 4000 patients” are cited as scientific evidence for the validity of the 75-g test. Yet they can only assign “consensus-level” evidence for their position. Moreover, they qualify their endorsement of a 75-g, 2h test as follows: “In view of the common use of the 100-g OGTT during pregnancy, a 100-g glucose load may be used in carrying out a diagnostic test and measuring following values as recommended by the ADA.” In this instance, the “consensus-based” diagnostic criteria endorsed by the American Diabetes Association may substitute for the CDA's own “consensus-level” recommendation.

I was curious about the rationale for the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada*'s recommendation that women diagnosed with gestational diabetes undergo an OGTT postpartum, given the

general recommendation to use the FPG test in clinical practice. In an interview, one of the committee members gave the following explanation:

It's based on the fact that there are some studies in that particular population that suggest a very high incidence of diabetes, and that goes undetected for reasons that probably are hormonal where the fasting glucose is pretty normal. And they're very high. And that was a subject of a debate, and it's not in my committee, so I can't really add anything (MR: That's fair enough) about the rationale beyond what is in the guidelines. But basically, from the discussions around the table, the evidence was there, some people were very much involved in doing those studies and seeing that and considering that as a major problem, a major risk for these women. And for whatever reasons that are still being looked at, their fasting glucose [levels] were not that high, seemed perfectly normal, but in the high 5s. And yet they were diabetic. And most of the approaches with these women are lifestyle anyway. But if we didn't do anything, they were all becoming diabetic, very shortly, in a way that was very evident. So it was thought that they had to be diagnosed as such to make them change their lifestyle.

This statement summarizes the committee's efforts to accommodate women who have recently given birth in their diagnostic criteria. A substantial proportion of women diagnosed with gestational diabetes remain diabetic after delivery when measured using the "gold standard" for diagnosing life-long diabetes (the 2-hour, 75-gram OGTT). Many of these women would not meet the FPG diagnostic criterion endorsed by the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* for routine clinical purposes, however. Therefore, the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* recommend the OGTT postpartum, an exception to the general rule that the FPG be used in clinical practice. The diagnosis of life-long diabetes, as represented here, can motivate recently-pregnant women to eat well and to exercise.

## IS DIABETES A DISEASE?

At various points during my research, I found myself ruminating about the distinctions in the field of medical anthropology between “disease,” “illness” and “sickness.”

In medical anthropology, “disease” usually refers to abnormalities in the structure and/or function of organs and organ systems, whether or not these are culturally recognized; “illness” indexes perceptions and experiences of certain socially-devalued states, whether or not these states correspond with disease (after Eisenberg 1977).

In 1980, Arthur Kleinman, recognizing that biomedicine represents but one medical system among many, suggested that “diseases” become socially significant when “illnesses” interface with local knowledge (Kleinman 1980, 72-73). He defined “sickness” as a blanket term that encompasses both disease and illness.

In 1982, Allan Young redefined “sickness” as “the process through which worrisome behavioural and biological signs, particularly ones originating in disease, are given socially recognizable meanings”(Young 1982, 270). That is, as bodily signs become socially significant, sickness sets in. When Young asserted that “sickness” socializes both “illness” and “disease,” biomedicine explicitly became grist for anthropological analysis.

By 1986, Kleinman was engaging how the human body mediates social and inner worlds, thereby expressing objective qualities (“disease”) and subjective experience (“illness”), but also social problems (Kleinman 1986). This perspective led to a concern with suffering, whether or not directly due to “disease” (Kleinman 1988; Kleinman 1995b; Kleinman 1995a; Kleinman 1996). In fact, the social conditions conducive to suffering can prompt disease, Kleinman and others have observed (Desjarlais et al. 1995; Farmer and Kleinman 1989; Kleinman, Das, and Lock 1997b).

Later in this thesis I directly engage the research agenda on suffering in medical anthropology (see Chapter 7). Immediately below, I address what the

distinctions between “disease,” “illness” and “sickness” imply for the statistical study of sweet blood.

*“That’s philosophy”*

An endocrinologist interviewed for this research project spontaneously distinguished between “disease” and “illness” when I noted that because the OGTT and the FPG diagnostic tests differ in sensitivity, I could not help but wonder if diabetes is really a disease. He said, “That’s philosophy.” There was an awkward silence. Then, he cleared his throat and said:

In terms again of how it is defined as a disease. In some people, it can certainly be a disease in the sense that it acutely causes patients to feel uncomfortable. If you define a disease as such, as not being at ease, so they can have polydipsia [extreme thirst], etc. It is certainly a *major* risk factor, if not a direct cause, of many complications.

The ensuing exchange highlighted for me the extent to which the diagnosis of diabetes in an individual currently depends upon statistics about populations. For the sake of simplicity, I did not explicitly address gestational diabetes in this part of the interview, which would have introduced an additional layer of complexity.

I said, “So it’s prognostic.”

He replied:

Now, you could say the disease is not diabetes, the disease is the diabetic retinopathy that makes the person blind. And the diabetes is a risk factor for that. All of that is a little bit philosophy, etc.

In effect, diabetes causes, is the main cause of blindness; it’s the main cause of renal deficiencies; the main cause of amputations. And it’s the direct cause. You don’t see those diseases, basically, if you don’t have the disease. So, that’s philosophy. I’ll leave that for philosophers to decide what’s the definition of a disease, etc.

I would not like, I would not be favourable to seeing something appear in the newspaper saying, ‘Ah! We now consider diabetes as not being a disease. It’s simply a risk factor.’

I considered myself duly warned. Next, touching on themes to be examined in Chapter 5, I asked:

What about recent developments in genetics? I mean, you have some of these things like maturity onset diabetes [of the young]. Is that, is that to your mind something that tends you to think that this is in fact a disease? If you find a genetic marker? Or with type 1, that it’s so associated with—

The endocrinologist broke in:

But again, how do you define a disease? It’s a, I mean, we define diabetes based on one measurement: glucose. (MR: Right) We know that it’s not the only thing. It’s a syndrome. It has many things happening at the same time. It’s simply a question of practicality that we define diabetes as that. But it is a sign that they have a metabolic disease.

There was a pregnant pause, followed by a defence of statistical probabilities as the bases for clinical interventions, and an acknowledgement that the meaning of the word “disease” in English does not translate literally into many other languages, including Canada’s other official language, French:

I’m a practical person. These kinds of discussions of saying, ‘Do we call it a disease or not?’ Will it harm the person? Absolutely, if we do nothing. And therefore, we have to intervene. That’s my approach. And if we do all the long discussions in English, we’ll then have to do the discussion in French. And the word ‘*maladie*’ might not have the same meaning, and then – Ahh!

He laughed, and I joined in. “Then you’re really in anthropological terrain,” I observed. The endocrinologist underlined again that diabetes constitutes a serious medical condition, if perhaps not a single disease, and then I recapitulated his remarks as follows:

That's very helpful. The way you describe it, actually, is very helpful. What I hear you saying is, 'Well, there may be some latitude, or some basis for discussion in certain fields, but as a practising physician, a treating physician, if you don't actually do something with these patients, or if the patients do not do something for themselves, then there are going to be big problems.'

"For sure," affirmed the endocrinologist. As exemplified in the interview excerpt above, contemporary biomedical researchers and clinicians understand diabetes to be a disease or family of diseases characterized by abnormally sweet blood, the presence of which signals the body's failure to transfer energy derived from food into its cells.

***"Disease" in the History, Philosophy, and Anthropology of Biomedical Science***

The notion, widely adopted in medical anthropology, that "disease" is synonymous with abnormalities in bodily structures or functions is of relatively recent vintage. Some 150 years ago, Claude Bernard, a pioneer in biomedical research, seized upon diabetes as the cardinal example of the relationship between normal and pathological physiology. For Bernard, the pathological state represents a quantitative extension of the normal state. The "classic symptoms" of diabetes—intense thirst, intense hunger, frequent urination, weight loss—could all be found in "normal" human bodies but less often and to a lesser degree, Bernard observed. Yet he could not find evidence of sugar in the urine of normal subjects. Bernard supposed that his equipment was not sensitive enough to detect "normal" urine sugar levels. His insistence on the lack of difference, other than degree, between normalcy and pathology expressed the triumph of eighteenth century rationalism over magic and religion as systems of thought. Bernard and other pioneers in biomedical research sought explanations for the onset and outcomes of sickness episodes in nature (see Keating in press).

George Canguilhem, writing in the 1930s, critiqued the mid-nineteenth-century supposition that the distinction between normalcy and pathology is quantitative, not qualitative. In other words, he maintained that pathologies differed fundamentally from normalcy: pathology was not an exaggerated instance of normalcy, but an entirely different bodily state. In critiquing Bernard's portrayal of diabetes, Canguilhem noted that sugar is never found in the urine of normal bodies. Further, Canguilhem maintained diabetes cannot be reduced to the presence of sugar in the urine ("glycosurea"). In other words, the pathology could not be reduced to this feature. Drawing upon knowledge not available to Bernard, Canguilhem argued that urine sweetens only when the body does not produce insulin, which is necessary to transfer sugar from the blood to the body's cells. The kidneys eventually evacuate glucose from the bloodstream, which sweetens the urine. Bodies bereft of insulin therefore differ qualitatively from "normal" bodies. It is not simply that people with diabetes have *less* insulin, Canguilhem underlined. Instead, they lack this hormone altogether. Regular insulin treatments can unsweeten urine and blood, he observed, but insulin treatments cannot entirely "normalize" diabetic bodies.

The characterization of type 2 diabetes in the 1950s altered the picture somewhat: a lack of insulin no longer characterized all, even most, cases of diabetes (Lieberman 1993). Instead, an absolute lack of insulin was found to characterize type 1 diabetes only. Type 2 diabetes, by contrast, could develop even when the body continued to produce insulin. Indeed, people with type 2 diabetes were found to produce insulin, but not be able to use insulin efficiently. What does this discovery imply for Canguilhem's argument and that of Bernard?

Canguilhem's criticism of Bernard does not accommodate the possibility of "the same" pathology stemming from diverse origins, but as illustrated further in the next two chapters, contemporary biomedical knowledge about diabetes exemplifies this possibility. Diabetes mellitus, as a diagnostic category, expressly includes people who cannot produce insulin *and* people who cannot properly use insulin. Type 1 and type 2 diabetes represent different pathologies if we take

insulin into account, as Canguilhem suggests we should. Yet both represent *types* of diabetes — kinds of the same thing — if we take the diagnostic criteria seriously. That “same thing,” as underscored in the above-quoted interview with an endocrinologist, is sweet blood. The sweeter the blood, the higher the risk for “complications.” In fact, as discussed earlier, the fasting plasma glucose (FPG) diagnostic test was recently revised to predict better the onset of “complications.” Thus, the difference between “normal” and “pathological” bodies is defined in terms of a quality of the blood, its sweetness. This difference can be expressed *quantitatively* because the probability of various “health risks” provides an external norm or standard against which pathology can be measured.

If the characterization of type 2 diabetes partially undoes Canguilhem’s critique of Bernard, the advent of the random clinical trial undermines Bernard’s definition of pathology. Insofar as pathology represents a quantitative extension of the normal state in contemporary biomedical knowledge about diabetes, the distinction between normalcy and pathology owes much to random clinical trials. Yet Bernard was firmly opposed to the use of statistics in medicine. Statistics may suggest that *most* people will fare well under a given treatment regime, Bernard and his contemporaries in physiology observed, but patients want to know whether *they* will survive. Bernard maintained that the role of the physician was to determine the exact causes of disease, so as to devise effective cures. He therefore studied particular individuals in clinics and laboratories — not statistical aggregates derived from the medical charts of large numbers of people. His belief in the uniformity of nature underpinned his analysis of the bodies of this or that patient as a case of this or that disease (Hacking 1990, 145; Canguilhem 1989 {1943,1966}, 29-45).

Statistics have eroded Bernard’s belief in determinism and in a universal human nature. Accordingly, modern-day clinicians and their patients routinely refer to “health risks” as well as “disease.” In so doing, they acknowledge that “risk factors” do not affect everyone in the same way. Statistics plot trends and

associations, thereby enhancing the powers of prediction, but they do not in themselves explain why some people succumb to disease while others do not.

In the nineteenth century, European statisticians sought to explain statistical variation in human populations with newly-discovered “laws of dispersion.” Birth, death, and sickness became predictable things in the aggregate, yet retained an aura of mystery, chance, and indeterminacy in the singular. Ironically, therefore, the expected level of control rose after eschewing the philosophy of determinism. Formally recognizing – even enumerating – the role of chance made it possible to predict trends in large populations, and through extrapolation, people could roughly figure the likelihood of certain events in the lives of particular individuals (see Daston 1988; Hacking 1990).

The random clinical trial, which became prominent in the latter half of the twentieth century, extended the reach of statistical technologies into human bodies. In the process, a metric for valuing life gained further definition. Random clinical trials, when extrapolated to individual patients, yield probabilities – not certainties – about the future prospects of particular patients. Such studies group together people with known pathologies and submit them to various treatment regimes. Calculated comparisons of populations over time became commonplace, giving rise to some contested negotiations over ethics, design, and the measurement of efficacy (Epstein 1997; Löwy 2000; Marks 1997 for concrete examples).

The current diagnostic criteria for diabetes hinge on epidemiological studies to establish the threshold between normalcy and pathology. Numerical values separate normalcy from pathology, and these values derive from a multitude of bodies congealed as clinical trial subjects. Canguilhem argued that such numbers, “mere” averages, *express* the difference between normalcy and pathology in numerical terms but that they do not capture the *essence* of genuine pathologies because they are not objective. With the invention and increased reliance on clinical trials, however, such numbers have taken on the trappings of objectivity. They can serve as standards for defining the present state of a body,

and they can also signal future prospects because populations have become “objective” social facts.

Recall that Bernard contended that statistical averages do not directly apply to real people, while Canguilhem asserted that a quantitative definitions of normalcy and pathology defy possibility because such definitions would hinge upon the calculation of averages. The diagnosis of diabetes, however, currently relies on “mere” averages as objective standards in distinguishing between normal and pathological states. When blood becomes so sweet that it predicts future health problems, the person embodies disease. In other words, statistical expertise has yielded benchmarks for defining an objective, pathological state.

Canguilhem’s understanding of pathology asserts that signifiers (human-wrought representations) can never replace what they signify (nature). Foucault, Canguilhem’s most famous student, underscored that through representation, human beings routinely and variably discern, even create, objects that they then seek to explain (Foucault 1971 {1970}). “Nature” has material dimensions that underpin and constrain what humans make of it, but the category is cultural. The “avalanche of printed numbers” that buried government offices, clinics, and laboratories alike in nineteenth-century Europe codified populations as natural phenomena in their own right (Foucault 1994 {1978}; Hacking 1982). Aggregates, as well as individuals, were found to exhibit properties and, even more than individuals, abide by laws. The increasing reliance on statistics has yielded standards – averages and other quantified qualities – that congeal large numbers of people and that distinguish them from one another.

Instead of defining disease (at least some of the time) as the quantitative extension of normal physiology, certain analysts might prefer, following Canguilhem’s lead, to define pathology as “absolutely different from physiological processes” (Keating in press, 12). Such a position implies that historians and ethnographers of biomedicine need not settle for epistemologies: we can analyze ontologies instead. This opportunity arguably exists because (at

least some) contemporary biomedical scientists grapple not only with biological variables, but also with pathological events such as infection and heart attacks.

My ethnographic account of recent changes to the diagnostic criteria for diabetes would suggest that such a position brackets malleability and variation in defining disease, and in particular, the contemporary fixation with risk. Through the rubric of risk, pathology is apprehended in the present by projecting it into a future time horizon. The reliance on the measurement of the sweetness of blood to detect “health risks” is part of a trend, one that regards bodily conditions such as elevated lipid levels, elevated blood glucose levels, and elevated blood pressure *as individual pathologies* because random clinical trials have shown that, in populations composed of people with similar characteristics, these conditions foretell “pathological events” (to use Keating’s terminology). Diabetes researchers, at the very least, regard “health risks” as *bona fide* diagnostic criteria.

The diagnosis of diabetes currently involves at least two kinds of intertwined synecdoches. First, the sweetness of blood indexes the patient’s present health and future prospects; the part (excess glucose in a blood sample) stands for the whole (the life of a particular person, encompassing immediate experience and long-term health risks). This relationship between a modicum of blood and the life of the person from which it was drawn hinges upon a second synecdoche, through which the patient is assigned membership to a group defined by numerical values: the part (an individual body) represents the whole (a normal or abnormal sub-population). The diagnosis of diabetes through the measurement of the sweetness of blood, in relation to time and the ingestion of calories, establishes distinct agglutinations composed of vials of blood, numbers, and bodies. Indeed, the two recognized diagnostic tests for lifelong diabetes, the FPG and the OGTT, establish slightly different configurations of blood, numbers, and bodies. By evoking “health risks” that could mar the future, the numerical values such used to diagnose diabetes express “normal” expectations about the length and other “qualities” of human lives. In these regards, they most definitely embody “objective” cultural norms.

In the part-whole relationships between blood, numbers, and bodies that enable the diagnosis of diabetes and (ideally) guide its treatment, the wholes define the parts, and vice versa. Numerical values and blood samples do not qualify as body “parts” in the usual way. Unlike the removal of an organ, drawing the amount of blood required to diagnose diabetes leaves the body essentially intact. The generation and circulation of numbers derived from multiple blood samples also leaves intact the bodies from which the blood came. Such numbers continue to reference the bodies from which they came, but through agglutination in statistical calculations, they may also regroup bodies and help define persons much further afield. As a result, statistics can become part and parcel of individual lives and collective bodies.

### **NUMBERED DAYS, VALUED LIVES**

As discussed and illustrated in this chapter, biomedicine has a distinct epistemology. It contrasts normalcy with pathology, and it groups together people with “the same” pathologies. In the case of diabetes, these tenets imply that groups of people are similar and different based on the sweetness of their blood. “Normalcy” and “pathology” refer here to a numerical range obtained by measuring the sweetness of blood in large human populations.

This chapter has documented how public health concerns informed the recent decision to lower the numerical threshold separating “normal” from “pathological” blood glucose levels using the simplest known diagnostic test, the fasting plasma glucose (FPG). Here, the quantitative definition of diabetes as a disease derives from the quantification of present and future quality of life. Public health concerns also prompted the recommendation that the FPG test become the clinical standard for diagnosing diabetes.

By diagnosing diabetes, clinicians aim to normalize the sweetness of their patients’ blood and in so doing, extend and improve lives. I have found it helpful to think about this aim — to normalize diabetic bodies and lives to the extent possible — as the outgrowth of a particular kind of literacy. Those who know

how to interpret the sweetness of blood constitute a collectivity endowed with specific technical knowledge. A differentiated sphere of human activity marked by the generation, reception, and conveyance of information about sickly sweet blood — a certain “culture of literacy” (after Godzich 1994) — has taken hold of some people across Canada and around the world. This knowledge base and associated practices are not static. Gatherings such as the annual CDA professional conferences help disseminate new knowledge, for example. In the process, the knowledge itself may subtly shift, as when physicians mine the results from a clinical trial conducted in the United Kingdom for their clinical significance in Canada.

Measuring the sweetness of blood situates particular bodies in reference to universal bodily processes, specifically the conversion of food to bodily energy. These processes may be universal, but not all bodies perform them equally well. Diabetics can break down food into glucose and infuse glucose into the bloodstream, but they cannot transfer glucose from the bloodstream into their bodies’ cells easily (in the case of type 2 diabetes) or at all (in the case of type 1 diabetes). A body that cannot convert food to energy easily or at all will suffer more and die more quickly than a body that makes such conversions with ease, all other things being equal. The sweetness of blood indicates how efficiently a given body can convert food to energy. As shown in this chapter’s presentation of physicians’ thoughts about the boundary between normal and pathological degrees of sweetness in human blood, the act of measurement has become imbued with predictive value. It can suggest that certain biomedical conditions, certain ways of life, and even certain kinds of death await people suffused with sweet blood. A common way of explaining insulin action, for example, is to compare insulin to a key that can unlock the body’s cells. To extend the analogy, through timely diagnosis, “lifestyle” modifications and other treatments, biomedical practitioners try to pick the lock and thereby secure the body’s future.

Insofar as people with diabetes themselves measure and interpret their blood sugar levels, they form part of a collectivity literate in what blood sugar

levels may imply for the immediate and distant future. They may be initiated into the regular reading of blood sugar by their health care team, starting with diagnosis, and they may be expected to produce evidence that they regularly measure their blood sugar levels. Those who inject insulin several times a day, for example, are expected to adjust their dosage based on these readings, with or without collaboration from a health care professional. “Diabetes care hinges on the daily commitment of the person with diabetes to self-management, balancing appropriate lifestyle choices, and pharmacologic therapy,” note the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada*. “Initial and ongoing education of the person with diabetes should be an integral part of diabetes management and not merely an adjunct to treatment.” (Meltzer et al. 1998, s3) The management of all cases of type 1 diabetes and most cases of type 2 diabetes requires that patients and physicians regularly monitor blood glucose levels. “The person with diabetes, in consultation with health professionals, should decide on the frequency of blood glucose measurements, taking into account the benefits of monitoring and the cost and pain associated with the procedure.” (Meltzer et al. 1998, s3, s4)

In portraying familiarity with blood glucose measures as a form of literacy, I do not mean that the body is a text to be read. Rather, the body *becomes* textual, or rather numerical, when represented in terms of blood glucose measures. Whether lying flat on a lab report or caught on the LED screen of a portable blood glucose monitor, such numbers index “lived experience” in the present and in the future. They handily summarize what it is to be “high,” “low” or “normal” and give these states standard definition.

Enumerating “normal” and “pathological” degrees of sweetness in human blood regroups certain people. Most obviously, measuring the sweetness of blood groups together people who meet the diagnostic criteria for diabetes. In this chapter, I have claimed that once diagnosed, a person with diabetes becomes kin—however distant—to all other people, living or dead, with this condition. In addition, the measurement and interpretation of sweet blood groups together

scientists, physicians, nurses, dieticians, social workers and other professionals who have an interest in diabetes. Researchers and other professionals who have an interest in diabetes acquire a certain expertise in what the sweetness of blood implies about a person's present life and future prospects. To the extent these professionals form a collective yet differentiated body, measuring the sweetness of blood is crucial. These readings provide their *raison d'être*, because they define their subjects and their subject matter.

Measures of the sweetness of blood have a cardinal dimension, since they refer to an absolute quantity of the amount of glucose in the bloodstream. They also have an ordinal dimension, since they index the amount and quality of life to be had in a particular body. The sweetness of blood supplies a rough-and-ready ranking of the length and quality of life remaining in particular bodies. Through "classificatory" kinship, populations and members thereof undergo definition, and to at least some extent, it may seem possible to exchange a rather nasty, brutal, and short existence for "normalcy." The possibility of exchanging one sort of future for another beckons, with different numerical values lending definition to the body corresponding to each sort of future. Further, the measurement of the sweetness of blood helps establish the relative value of different sorts of futures, and thus the desirability of exchanging a body marked by sickly sweet blood for one that approaches normalcy.

By establishing the desirability of certain bodies when compared to others, and the possibility of exchanging dangerously pathological for "normalized" bodies, the measurement of blood glucose helps constitute "regimes of value" (Appadurai 1986). The biomedical definition of diabetes, the premium placed on "high risk" patients undergoing the diagnostic test, and the manner in which biomedical knowledge interfaces with the lived experience following diagnosis all pivot upon the understanding that it is possible to "trade up" to a better life – one in which sweet blood exacts a minimum toll.

To “trade” in this manner is more than a figure of speech, for I argue that the interpretation of blood glucose measures entails distinct, but intersecting, commodity situations.

In the contemporary period, to detect dangerously sweet blood, Canadian doctors typically order FPG tests. Patients usually go to an outpatient clinic of a public hospital in a fasting state, typically first thing in the morning. A nurse extracts blood and sends the sample to a laboratory for analysis; once analyzed (converted into numbers), the laboratory routes the results to the physician; the physician then interprets and relays the results to the patient. The nurse, the laboratory technician, and the physician all receive monetary payment for their services because their labour is a commodity. In Canada, these costs are typically covered through public health insurance, although private insurance will often cover testing in for-profit laboratories, which entails less “time loss” and overall inconvenience to the patient.

In addition to the professionals’ labour, the blood sample itself takes on certain qualities of a commodity: it is a valued thing intended for exchange, for displacement from one party to another (after Appadurai 1986, 9). Since the body continually regenerates its blood supply, and someone or something must be seen as renewable, replaceable, or expendable for commodification to take place (after Strathern 1992a). Blood samples are replaceable in another sense, in that they can be made to yield knowledge under the auspices of biomedicine. That is, professionals convert the blood sample into a number endowed with social significance. A patient who provides blood for a diabetes test sacrifices some time and endures some discomfort, even anxiety, to satisfy “the need to know.” In this sense, patients “barter” a replaceable part of their body, a period of time, and possibly unpleasant emotions in exchange for knowledge. The recommendations for screening in the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* seek to establish when these “trade-offs” between inconvenience and money to pay for the test are worthwhile.

In addition to commodifying a body “part,” a blood sample, my research suggests that the diagnosis of diabetes commodifies the source of that blood sample, the patient’s body *in toto*. The patient’s entire future becomes part of the equation because the act of interpreting blood glucose measures situates the patient’s body in reference to populations endowed with various kinds and degrees of health risks. Scientific research on diabetes has established blood sugar measurement as a way of comparing the value of bodies with and without diabetes, and of bodies endowed with varying degrees of “control” over diabetes.

Populations, as well as the individuals who compose them, routinely undergo commodification in biomedicine. As a result of epidemiological research in particular, populations appear in biomedicine as fungible entities, albeit ones that cannot be exchanged for one another except through substitution (Strathern 1992a cf.; Appadurai 1986). Unsweetening blood, one diabetic at a time, promises to produce a healthier population, and might lower health care costs. The maintenance and growth of human bodies can yield diverging futures, whose desirability varies. The concern in the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* with ensuring that the new clinical diagnostic standard, the FPG, approximates the “gold standard,” the OGTT, turns on the promise of identifying those at highest risk for the “complications” of sweet blood.

When individuals and populations are assigned values and portrayed as exchangeable entities under the auspices of biomedicine, they satisfy the two main criteria of commodification: assigning values and defining possibilities for exchange (Appadurai 1986). Setting values and envisaging possibilities for exchange presuppose classification. In the case of biomedicine, the commodification of individual human beings and of whole populations pivots on classifying human bodies as “normal” or “pathological.” Measuring the sweetness of blood provides a way of establishing how normal, or how pathological, a given person’s body is. When classificatory kin reckoning establishes the value of

various human lives via the measurement of the sweetness of human blood, this “exchange value” is not tantamount to a price (cf. Gregory 1982, 67-68).

In the definition of diabetes as a disease and in its management, ideas and practices that confer *exchangeability*, as opposed to completed transactions, provide the basis for commodifying human bodies. In turn, the commodification of bodies provides the basis for exchanging a blood sample for knowledge. Here value does not arise principally *through* exchange (cf. Appadurai 1986, 9), which conventionally involves displacement of an object (such as a blood sample) from one party to another. Instead, *imagining* the possibilities for controlling bodily composition *over time* evaluates bodies based on the sweetness of their blood. While time factors into every commodity situation, the extent to which the commodification of bodies and their parts in biomedicine hinges upon the valuing of time lived in individual human bodies is perhaps unique.

My argument underscores that commodity candidacy – “the standards and criteria (symbolic, classificatory, and moral) that define the exchangeability of things in any particular social and historical context” – precedes transactions, rather than arising from them (after Appadurai 1986, 13-15; cf. Goddard 2000). Once something or someone is regarded as a *potentially* replaceable or exchangeable, commodification has taken place (cf. Appadurai 1986, 9). Commodification can thus take place in the absence of exchange. In other words, I am arguing for a distinction between *commodities* (things offered in exchange for, or to replace, something else) and *commodification* (ideas and practices that construe a thing as exchangeable or replaceable). Commodification occurs when people evaluate any thing — including a human body, in part or in entirety, for a finite period of time or over the life span — as potentially exchangeable or replaceable.

The diagnosis of diabetes demonstrates that commodification can alter the biographies of persons or things without these persons or things becoming commodities (cf. Appadurai 1986, 9, 13; Marx 1954 {1887}, 43, 88-89; Strathern 1992a, 171-172, 178). The blood sample necessary to diagnose diabetes becomes

a commodity (it enters the possession of others), but not the person from whose body it came. Yet unless the human body is understood as a pliable, valuable thing (the essence of commodification), the diagnosis of diabetes has little utility. The commodification of human bodies provides the rationale for exchanging blood samples for knowledge. The patient's "future self" is construed as the main beneficiary of diagnosis.

This conceptualization bestows moral responsibility for the "future self" on the patient's "present self" as well as on health professionals. The patient's body appears as a malleable entity whose future inhabitant should profit from efforts by the patient and the professional to detect and redress sweet blood. In this sense, patient's body constitutes an entity that the patient's "future self" will inevitably inherit from the "present self." The worth of the body to the "future self" may augment through judicious application of biomedical expertise in the here and now. The "present self," the "future self" and health professionals appear as parties to a transaction involving the patient's body. The patient's body does not change hands, "owners," when the diagnosis of diabetes is made, although the identity of the person may shift and kinship ties may undergo elaboration to accommodate this new knowledge. Over time, the health professionals in whose hands the patient's body is entrusted may change. Furthermore, the patient's hands themselves will subtly change, as will the entirety of the patient's body.

Through cell death and reproduction, a body replaces itself over time, but it changes as it ages. Biomedical research and clinical practice aims to stave off death and disease, and so the possibility of opting for a better life may appear both attractive and feasible. The numerical values derived from blood samples for diagnostic and monitoring purposes represent the bodies from which they were drawn, and, when compared with statistics derived from bodies akin in terms of blood glucose levels, these numbers index the years and quality of life in store for particular persons.

An article on "the global cultural economy" that emphasizes the transformation of identities, as opposed to the shaping of human bodies, advances

an argument that parallels my analysis of how biomedical expertise commodifies human bodies (Appadurai 1990). In this article, Appadurai observes that as education, travel and mass media expand frames of reference beyond immediate experience, “categories of being” multiply into a plethora of “possible lives” that appear desirable or abhorrent, attainable or not. In the case at hand, measuring the sweetness of blood codifies lived experience and ranks “possible lives.”

Through synecdochal relationships between blood samples, bodies and numerical values, populations and their constituent individual members become construed as equivalent kinds of entities whose worth differs (cf. Strathern 1992a). Therefore, biomedical renderings of human bodies may result in “commodity situations” in which alienation or detachment do not take place (cf. Appadurai 1986; Goddard 2000; Gregory 1982; Mosko 2000). Any one individual body or any particular human population cannot be detached or alienated from its own future. Even a blood sample drawn to make the diagnosis of diabetes continues to represent the body from which it came; as long as it is systematically labelled and filed, it represents its source.

In this chapter, I have taken pains to outline how and why the sweetness of blood can express the value of a long, healthy life. To conclude, I wish to underline that current diabetes-related research and clinical practice implicitly acknowledge the limited extent to which any one person can embody health, for death by assorted causes is in the offing for all. After a certain number of years of life, death appears “normal.” Still, differences – inequalities, even – mark the “life chances” of groups of people suffused with sweet blood as compared to people whose blood contains “normal” amounts of glucose. Furthermore, people with sweet blood will not all live to the same age, nor in the same “degree” of health. The chances of long, healthy lives increase to the extent that the sweetness of blood falls within the “normal” range.

## 4. “Typing” Sweet Blood, Valuing Lives

I have been asked many times *which* diabetes is central to my research. Depending on how centrally sweet blood figures in their day-to-day lives, interlocutors have used a variety of terms to refer to conditions that, reflecting international trends, the *1998 Clinical Practice Guidelines for the Treatment of Diabetes in Canada* call type 1, type 2, and gestational diabetes (Meltzer et al. 1998). During fieldwork, I sought to discern when the “typing” of sweet blood became relevant, and for whom, rather than organizing my research around one or more kinds of diabetes currently recognized within biomedicine.

While the previous chapter focused on how the diagnosis of diabetes hinges upon the sweetness of blood, in the present chapter, I analyze distinctions among people who have dangerously sweet blood, but for different reasons. These reasons are important for clinical treatment and management, as well as for research. More specifically, this chapter examines how biomedical researchers and clinicians currently classify “types” of sweet blood, it explores the history of this classification system, and it places biomedical classification within the ken of anthropological theory about exchange.

My analysis undercuts the notion that human beings comprise discrete, irreducible wholes across “the West” – a notion that recurs as a truism and a point of contrast in the anthropological literature. Distinguishing among “types” of sweet blood based on their origins, on their different natures, bestows upon human bodies the status of priceless valuables. This status gives rise to partitioning human bodies (drawing and analyzing the chemical composition of blood samples, for instance) and reconstituting them as members of statistically-fashioned populations, the better to secure health and to minimize suffering.

### VALUABLE BODIES AND ORIGINAL PARTS

My analysis of the “typing” of sweet blood in this chapter draws heavily on Marilyn Strathern’s efforts to refuse functionalist “just because” readings of

valuation in Melanesian gift exchange and barter (see Strathern 1992a). She takes issue with anthropologists' emphasis on ratios to construe the "true worth" of the things and people implicated in exchange. The abiding concern in anthropology with the practical and social utility of exchange, she argues, has elided analysis of *how* transactions constitute human subjects. Strathern observes that exchanged items *replace* one another, and she argues that exchange depends upon the perceived capacity of one thing to substitute or stand for another. She asks what allows "like" items to be classified as such, as well as why "unlike" items may be classified as equivalent in worth. Transactions neither reflect the equivalence of the items exchanged, nor do they reflect the rank of the transactors, says Strathern. Instead, she argues convincingly, transactions *establish* the substitutability of the items in question, while also objectifying or defining the worth of the people engaged in exchange (cf. Appadurai 1986, 13-15; Gregory 1982).

In applying these suppositions to the "typing" of people with diabetes under biomedicine, this ethnographer had to begin by picking apart the implication – if not the stated intention – that Strathern's ruminations have particular or even exclusive relevance for Melanesia.

Strathern has argued that the circulation of people, objects, and knowledge in Melanesia constitutes persons in ways that diverge sharply, even diametrically, from personhood in "the West" (Strathern 1996, for example). In explaining how the exchange establishes worth, Strathern notes that "a Melanesian person is a composite, multiple entity, constituted by the acts of others, internally differentiated in the various origins of his or her being" (Strathern 1992a, 178-179). She adds that Melanesian persons are also partly constituted through their own actions over time, and the transformation or conversion of these acts into other things. "One's own acts are returned, then, *in another form...*" through serial substitution (Strathern 1992a, 188, emphasis in original). Contrasting the current location of (personified) objects with their origins affixes value; these comparisons take stock of the rise and fall of fortune, and fortunes. Through a

local system of accounting, acts-*qua*-objects originating with the individual and with others accrete, composing the Melanesian person (Strathern 1996; Strathern 1988). In reckoning and extending kin networks through exchange, these acts-*qua*-objects may help constitute groups, as well as differences among their members. For example, “wives” in a given society may occupy a shared subject position, but they will not all embody the same capacities, nor will they all be held in the same esteem (cf. Lévi-Strauss 1949).

Strathern’s contention that personhood in Melanesia differs fundamentally from its Western counterpart has broad acceptance among anthropologists, as illustrated by a recent review article that leans explicitly and heavily on Strathern to argue that Weiner misconstrued Melanesian gift exchange. This review article concludes:

...the basic conceptual elements of Weiner’s analysis are consistently isomorphic with prevailing Western notions and presuppositions and at considerable variance with those of much recent Melanesian ethnology; as regards persons as unitary individuals rather than partible beings; possession and ownership as relations between things rather than as relations between persons; objects as radically distinct from, rather than as parts or tokens of, persons; an inherent dichotomy between moveable and immovable objects; discrete units (individuals, groups, objects) rather than relations; and emphasis on ‘the need to secure permanence’ in an entropic world rather than on social processes encompassing both expansion and contraction, on integration and disintegration. (Mosko 2000, 392)

At this juncture, I cannot assess Weiner’s contention that the paradox of “keeping-while-giving” – not the “norm of reciprocity” expounded in anthropological scholarship – has universal application, and therefore holds across Melanesian, “the West,” and all other societies, past and present (see Weiner 1992). And I do not contest the suggestion that Melanesians construe personhood in ways that may differ significantly, even radically, from “the West.” Yet I find it

productive to distinguish heuristically between personhood – a social identity – and the material human body. The human body’s materiality endows it with features and properties that interface with social identities, but social identities and individual bodies are not always synonymous (pace Harris 1989; Schepers-Hughes and Lock 1987).

Personhood is seen as a feature or “part” of the material human body in “the West,” which dissolves the notion that “Westerners” invariably constitute unitary, discrete, unique social beings. Under a biomedical gaze (see Foucault 1973), bodies do not constitute irreducible individuals, but a divisible (“dividual”) complex whose parts together secure life – but only for so long (cf. Dumont 1985; Strathern 1988). In biomedical terms, death occurs when the inner machinery grinds to a halt. At this point, which remains subject to manipulation and to debate in many quarters, the person who inhabited the body is pronounced “gone” (Hogle 2000; Lock 2000). “Western” persons may invoke providence, heritage, character, and any variety of deliberate acts and unintended consequences to explain why certain bodies remain alive and healthy, while others do not. In so doing, they confirm the value of a long life replete with “quality.”

Under the auspices of biomedicine, therefore, the human body exhibits many of characteristics of Melanesian persons identified by anthropologists such as Strathern. More specifically, biomedical knowledge portrays human bodies as partible beings; as assemblages that each developed from a single cell containing genetic substance inherited from two lineages; as physical entities that seat persons whose actions and interactions help shape the body until death, inevitably, occurs. Indeed, the “reductionist” epistemology often imputed to biomedicine locates disease in “defective” body parts and “dysfunctional” processes. The parts, the wholes, the origins, and the acts understood in “the West” to compose bodies and persons stand worlds removed from heaps of yams, armfuls of fish, and newly-wed brides in Melanesia. Yet biomedical researchers and clinicians, like Melanesians, have an account of how food, activity, and reproduction help compose bodies, ground experience, and delimit life spans. In

fact, by internalizing statistical accounts of bodily growth and biomedical accounts of development (see Butt 1997), some Melanesians might qualify as “biomedical thinkers,” at least some of the time.

### **SWEET PATHOLOGY: CAUSES VERSUS EFFECTS**

One of the notable features of current diagnostic criteria for diabetes is that they do not attribute cause: knowledge about *how* or *why* a given body developed sweet blood is not required to make the diagnosis of diabetes. For the purposes of treatment and management, however, it is important to discern the origins of a particular case of sweet blood. Thus, the diagnosis of diabetes inaugurates the “typing” of people with diabetes under biomedicine, which the attribution of origins complements and extends.

The erosion of the doctrine of determinism during the nineteenth century in favour of “statistical laws” underpins the possibility of diagnosing pathology even when the origins of a particular case of pathology remain uncertain (Hacking 1990). Statistical formulae were found to predict bouts of illness, deaths and “needs” in human populations. Accordingly, many new categories emerged with which to “type” and govern people (Hacking 1986; Foucault 1994 {1978}). The interest in discerning causes did not disappear, but it was recast through an emphasis on prediction. The “typing” of people with diabetes in contemporary biomedicine reflects this over-riding concern with predicting and controlling the future. Along with detecting blood glucose levels that predict future health problems, the clinician classifies sweet blood by origins to formulate recommendations and prescribe treatments. Under biomedicine, the classification of the origins of disease derives from research.

Dr Hertz Gerstein, introduced in the previous chapter, underlined that the current diagnostic criteria for diabetes do *not* encompass causality during a presentation accorded him as the “young scientist” of the year at the 1999 CDA Professional Conference. His remarks bear extensive quotation here because he neatly summarizes the distinction between the current diagnostic criteria for

diabetes and attributions of origins, while also underscoring that the diagnosis of diabetes indexes the probability of *certain* health risks.

He opened by noting that he was the first to receive the Young Scientist Award for epidemiological research, suggesting recognition of “the value of clinical epidemiology as a methodology that is important and useful for answering scientifically important questions that are relevant to both diabetes and to endocrine research.”

Before embarking upon the subject on the presentation (how blood glucose and insulin levels correlate with cardiovascular disease), Dr Gerstein reviewed how epidemiologists construe risk, as opposed to causality:

I think it’s important that we understand what a risk factor is from an epidemiologic context. A risk factor is just something that you can measure in a person or a population which is associated with some subsequent problem down the line.... The most important thing to keep in mind is that epidemiology tells you virtually nothing about causality. So there are many risk factors that are modifiable risk factors that are not necessarily causal risk factors. Smoking is a causal risk factor, and that has been established by all sorts of studies, even epidemiologic ones. But albuminuria clearly is not: protein in the urine doesn’t cause renal failure.... And in fact, we can really make very little inferences about what causality is, and it’s not even important [clinically].... It is important for understanding disease.

Dr Gerstein then underscored that the current interest that attends the correlation between elevated glucose levels and elevated cardiovascular risk dates back only to the early 1990s.

I can tell you that when I started looking at this about five or six years ago, there was a tremendous amount of nihilism about that possibility. Many people said it doesn’t matter, you have diabetes, that’s it, your glucose level’s not important. And this was commonly heard in all sorts of venues and written in the literature. And then in 1993, 1994, some papers started to appear

in which people looked at the risk of cardiovascular outcomes according to the glycemic levels.

Dr Gerstein noted that “these studies consistently showed that for every 1% increase in glycosylated hemoglobin, there is a significant increase in relative risk of cardiovascular disease that ranges from about 12% to 30%,” and hence, blood glucose levels constitute a continuous risk factor for “cardiovascular events.” In other words, among diagnosed diabetics, the average amount of sugar in the bloodstream correlates with the frequency of cardiovascular disease. These remarks led into a reminder that cardiovascular risk and, indeed, life expectancy do *not* figure in the definition of diabetes:

It’s important to go back and say, ‘Is that [the observed association between elevated blood glucose levels and cardiovascular risk] relevant to the diagnosis of diabetes?’ And let me remind you what the diagnosis of diabetes was based on and what this disease is. Diabetes was never defined as a risk factor for cardiovascular disease. The glucose thresholds that identified people as having diabetes or not diabetes, these glucose thresholds were identified in epidemiologic studies in which the outcome was not cardiovascular disease, but was retinopathy and renal disease. And in fact, a 2-hour [oral] glucose [tolerance test] of 11.1 right there strongly predicts a high risk of retinal and renal disease. These are prospective epidemiologic studies. These criteria had absolutely nothing to do with cardiovascular disease. And therefore there is absolutely no reason to believe that these thresholds apply to cardiovascular disease: the thresholds could be lower or higher for cardiovascular disease.

And that’s important to keep in mind as you read all those papers that have come out in the last year or two saying that the CDA and the ADA criteria [using the fasting plasma glucose test] are not as good as the WHO criteria [using the oral glucose tolerance test], and [that] we should be doing 2-hour glucose levels

because they're better predictors of mortality than are the fasting glucose levels. If we're talking about diabetes, diabetes was not defined as a disease that predicts mortality or a disease that predicts cardiovascular disease. And so if in fact we're worried about the glucose levels that predict mortality or cardiovascular disease, let's forget about the diagnosis of diabetes completely. We probably have to do epidemiologic studies to define a different disease or a different glucose threshold, somewhere else, that defines an increased risk for cardiovascular disease. Then we can have meaningful debates about whether the WHO or the ADA criteria for diabetes are better predictors of cardiovascular events.

After providing this primer on epidemiological knowledge embedded in the current diagnostic criteria for diabetes, Dr Gerstein introduced the concept of "dysglycemia."

"Dysglycemia" is a term coined to encompass the correlation between sweet blood and heart disease. In a published paper on the topic, Dr Gerstein observes:

Several epidemiologic studies...suggest that this relationship [between blood glucose and cardiovascular risk] is not confined to the diabetic range; non-diabetic levels of fasting and post-prandial hyperglycaemia, that may even be lower than those associated with impaired glucose tolerance, are also associated with an increased risk of cardiovascular disease. Evidence is therefore accumulating that dysglycemia (i.e., raised glucose levels above some low, as yet undefined, threshold) is a continuous risk factor for cardiovascular disease. (Gerstein 1998, s9)

The global importance of blood sugar measurement expands greatly when – similar to smoking, blood pressure and lipid levels – the sweetness of blood represents a continuous risk factor for cardiovascular disease, the leading cause of mortality in Canada, the United States, and many other countries. "Dysglycemia"

therefore vastly expands the numbers of people whose futures can be divined by measuring the sweetness of their blood, and it shrinks the blood glucose range defined as “perfectly normal.”

To explain why sweet blood increases the risk of cardiovascular disease and other “complications,” Dr Gerstein pointed out that the mean blood glucose level among humans resemble that of other species, underscoring kinship between human beings and other animals:

When I presented this information recently, someone pointed out that glucose levels are very highly conserved across species. And I didn’t know that because I don’t do animal research. But I went to a source, a biology data book, I found it in the library, and sure enough, I looked up the mean glucose levels in a whole range of species. These are not all fasting glucose levels; I certainly would not want to do a fasting glucose level on an alligator [audience laughs]. However, it certainly appears that glucose levels are conserved. So cows, sheep, swine, horse, dogs, etc.

So it looks like biology, and through evolution, has kept glucose levels within a narrow range, possibly because hyperglycemia and high glucose levels are somehow bad for you, biologically, and somehow bad for at least vertebrates, and even octopuses and some other invertebrates.

So what about non-diabetic glucose levels? If the glucose thresholds for diabetes are relevant for cardiovascular disease, let’s look at everybody; let’s see if we can find some evidence that nondiabetic glucose levels are important for cardiovascular disease [in humans].

According to this formulation, people with sweet blood deviate not only from what is “normal” for humans but also from cross-species norms. “Normalcy,” construed as the rational product of evolution, seems natural. While “dysglycemia” is certainly not a “type” of diabetes, Dr Gerstein’s efforts to define the point at which, on average, blood becomes so sweet that it predicts

cardiovascular disease underscore historical and practical contingencies inherent to the classification of pathologies.

Dr Gerstein's introduction to "dysglycemia" at the 1999 CDA Professional Conference reflects a tension between ascribing to humankind a biological unity, rooted in a common evolutionary past, while also distinguishing among human beings' life chances, as indicated by the nature and severity of diseases likely to befall them. With "dysglycemia," many more people may "relate" to blood sugar levels as a measure of their future well being. "Relative risk" may thus refer not only to probable differences between the health prospects attending different groups of people under varying circumstances, but also the process of establishing classificatory kinship among people whose bodies currently exhibit features suggesting comparable future health status. As illustrated by Dr Gerstein's remarks, these kin relationships among humans may elaborate lines of biological descent between humans beings and other species, for evolutionary theory construes the capacity to convert food into glucose as a "primitive" function that can become impaired in humans and in "lower" animals alike. The origins of sweet blood and its effects on life expectancy and quality of life in humans thus appear to be tied to an evolutionary past, partly shared with other species.

To reiterate, correlations between the sweetness of blood and *select* bodily states ground the very definition of diabetes and of dysglycemia. The statistical rendering of "quality of life" – rather than life expectancy – currently sets the boundary between normal and pathological blood glucose levels. As underscored by Dr Gerstein, the OGTT diagnostic criteria for diabetes index the average likelihood of developing eye and kidney disease, but not on the likelihood of "premature death."

The extent to which sweet blood contributes to mortality rates remains unknown. Dr Gerstein's research questions just how sweet blood may become before posing a health hazard, and explicitly aims to take cardiovascular disease and "premature death" into account. "Dysglycemia" aside, estimating total

diabetes mortality is fraught with uncertainty, even in countries such as Canada with sophisticated health information systems. Recall that type 2 diabetes often goes undiagnosed; undiagnosed cases of diabetes may contribute to deaths coded as, for example, cardiovascular in nature. Furthermore, diabetes is not consistently coded either as a “contributing cause of death” or as “the underlying cause of death” on death certificates.

In 1997, Statistics Canada researchers determined that the disease was listed as “the underlying cause of death” in only 28% of all death certificates mentioning diabetes, replicating the results of an earlier study carried out in Canada’s least smallest and least populous province. The Prince Edward Island study also matched diagnosed cases of diabetes in health insurance records with the death certificates, and found that diabetes did not appear on the death certificate *at all* for 41% of all diagnosed cases of diabetics. That is, in the estimation of the physician who signed the certificate, the confirmed presence of sweet blood neither hastened nor precipitated death. In two thirds of these cases, the underlying cause of death was listed as cardiovascular disease, renal disease, or gangrene; yet all three are “complications” of diabetes (Canada. Health 1999c, 27 for discussion).

It may seem intuitive that people would prefer not to be blind, require dialysis to survive, or undergo kidney transplantation, but it still bears underlining that statistics ramify these social preferences in the diagnosis of diabetes. In other words, the diagnostic criteria do not “naturally” demarcate diminished utility and worth. Disability rights activists routinely contest the intuition that life lived with a disability such as blindness or limb amputation inherently leads to suffering on a daily basis, and therefore they selectively critique *and* endorse clinical interventions (Rock 2000c for discussion). The recent vintage of current standards and techniques for diagnosing diabetes, the subject of the remainder of this chapter, also highlights that “nature” mediated by “culture” gives rise to disease categories.

## **“TYPES” OF SWEET BLOOD AND THEIR ORIGINS**

The *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* departed from the nomenclature proposed by the American Diabetes Association in 1979 and adopted by the Canadian Diabetes Association in 1982 for the two main clinical presentations of diabetes. Insulin-dependent diabetes mellitus (IDDM, or type I diabetes) would hitherto be known as type 1 diabetes, while non-insulin-dependent diabetes mellitus (NIDDM, or type II diabetes) would be known as type 2 diabetes (Meltzer et al. 1998, s4-s5).

Upon tabling a draft version of the new clinical practice guidelines were tabled at the 1997 CDA Professional Conference, Dr Denis Daneman explained these changes as follows:

The first thing to say is that from today in Canada, we're going to get rid of IDDM and NIDDM. These are therapeutically based classifications, and not pathogenically defined classifications. The ADA (American Diabetes Association ) has gotten rid of those two terms [in 1997], and we're getting rid of them as well. For those people who have been NIDDM, but receiving insulin, will forever be Type 2. We're going to retain Types 1 and 2. And as you can see [from the accompanying slide] the new numbers are Arabic and not Roman, because the Americans were very worried about Type 1 and Type 11.

In other words, the American expert committee feared that member of the public would confuse the Roman numeral “II” for the Arabic numeral “11,” which would imply the existence of eleven common types of sweet blood. The final document underlined that classification based on “insulin dependence” had led to considerable confusion. “People with any form of diabetes may require insulin treatment at some stage of their disease. Such use of insulin does not, in itself, classify the patient.” (Meltzer et al. 1998, s5)

After explaining the change in nomenclature, Dr Daneman introduced the defining features of type 1 and type 2 diabetes:

So what is type 1 diabetes? It encompasses diabetes that is primarily a result of pancreatic beta-cell destruction and that is prone to ketoacidosis [excessive acid in the blood resulting from the liver converting fat stores to energy]. There are both the autoimmune varieties, and the non-immune varieties that have been more recently recognized.

Type 2, or the most common type of diabetes, may arise from predominantly insulin resistance with relative insulin deficiency to a predominantly insulin secretory defect with insulin resistance.

So while the diagnosis of diabetes pivots on the measurement of the sweetness of blood, the distinction between type 1 and type 2 diabetes is based on the mechanisms within the body that sweeten blood.

Diabetes can also arise through mechanisms other than those implicated in type 1 and type 2 diabetes, a possibility that the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* accommodate through a catch-all category for “relatively rare” types. Dr Daneman explained:

The third classification encompasses other forms of diabetes, and this includes a very wide variety of relatively rare conditions, which consist mainly of a number of categories. Firstly, specifically genetically-defined forms of diabetes, such as the MODY [maturity-onset diabetes of the young] types of diabetes, or diabetes associated with other diseases such as cystic fibrosis, or ion overload, or drug use.

“And finally, the last category is that of gestational diabetes,” Dr Daneman said, for, as noted in the previous chapter, the sweetening of blood during pregnancy bodes ill for the future mother and her child alike.

The final published version of the *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* summarized this four-fold taxonomy in the following table (see Figure 13), in turn adapted from a report commissioned by the American Diabetes Association (Report of the Expert Committee on the Diagnosis and Classification of Diabetes Mellitus 1997). As this table shows, the

**Figure 13:**

**Classification of diabetes mellitus**

<b>Type 1 diabetes mellitus</b> (beta-cell destruction, usually leading to absolute insulin deficiency)	
<ul style="list-style-type: none"> <li>• Immune mediated</li> <li>• Idiopathic</li> </ul>	
<b>Type 2 diabetes mellitus</b> (may range from predominantly insulin resistance with relative insulin deficiency to predominantly secretory defect with insulin resistance)	
<b>Gestational diabetes mellitus</b> (onset or recognition of glucose intolerance in pregnancy)	
<b>Other specific types</b>	
<i>Genetic defects of beta-cell function</i>	<i>Genetic defects in insulin action</i>
<ul style="list-style-type: none"> <li>• Chromosome 12, HNF-1 alpha (formerly MODY 3)</li> <li>• Chromosome 7, glucokinase (formerly MODY 2)</li> <li>• Chromosome 20, HNF-4 alpha (formerly MODY 1)</li> <li>• Mitochondrial DNA</li> <li>• Others</li> </ul>	<ul style="list-style-type: none"> <li>• Type A insulin resistance</li> <li>• Leprechaunism</li> <li>• Rabson-Mendenhall syndrome</li> <li>• Lipotrophic diabetes</li> <li>• Others</li> </ul>
<i>Diseases of the endocrine pancreas</i>	<i>Endocrinopathies</i>
<ul style="list-style-type: none"> <li>• Pancreatitis</li> <li>• Trauma pancreatectomy</li> <li>• Neoplasia</li> <li>• Cystic fibrosis</li> <li>• Hemochromatosis</li> <li>• Fibrocalculous pancreatopathy</li> <li>• Others</li> </ul>	<ul style="list-style-type: none"> <li>• Acromegaly</li> <li>• Cushing's syndrome</li> <li>• Glucagonoma</li> <li>• Pheochromocytoma</li> <li>• Hyperthyroidism</li> <li>• Somatostatinoma</li> <li>• Aldosteronoma</li> <li>• Others</li> </ul>
<i>Infections</i>	<i>Uncommon forms of immune-mediated diabetes</i>
<ul style="list-style-type: none"> <li>• Congenital rubella</li> <li>• Cytomegalovirus</li> <li>• Others</li> </ul>	<ul style="list-style-type: none"> <li>• "Stiff-man" syndrome</li> <li>• Anti-insulin receptor antibodies</li> <li>• Others</li> </ul>
<i>Drug or chemical induced</i>	<i>Other genetic syndromes sometimes associated with diabetes</i>
<ul style="list-style-type: none"> <li>• Vacor</li> <li>• Pentamidine</li> <li>• Nicotine acid</li> <li>• Glucocorticoids</li> <li>• Thyroid hormones</li> <li>• Diazoxide</li> <li>• Beta-adrenergic agonists</li> <li>• Thiazine</li> <li>• Dilantin</li> <li>• Alpha-interferon</li> <li>• Others</li> </ul>	<ul style="list-style-type: none"> <li>• Down's syndrome</li> <li>• Klinefelter's syndrome</li> <li>• Turner's syndrome</li> <li>• Wolfram's syndrome</li> <li>• Friedreich's ataxia</li> <li>• Huntington's chorea</li> <li>• Laurence-Biedel syndrome</li> <li>• Myotonic dystrophy</li> <li>• Porphyria</li> <li>• Prader-Willi syndrome</li> <li>• Others</li> </ul>

DNA = deoxyribonucleic acid  
HNF = hepatocyte nuclear factor  
MODY = maturity onset diabetes of the youth.

Source: *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* (Meltzer et al. 1998, s5), adapted from Report of the Expert Committee on the Diagnosis and Classification of Diabetes Mellitus (1997).

root causes for sweet blood remain unclear in many cases. In particular, note that type 1 diabetes is defined as “idiopathic,” meaning “without a known cause.”

Currently, as indicated by Dr Daneman’s remarks and in Figure 13, researchers and clinicians regard type 1 and type 2 diabetes as stemming from distinct origins and as “under control” to varying degrees, giving rise to different treatment trajectories. Insulin treatment is always required to control type 1 diabetes, but it may also be prescribed for type 2 diabetics if a person’s blood remain sweet even when taking several oral agents.

### **OF HISTORIES AND TYPES**

In interviews and informal dialogues, physician-researchers repeatedly told me that type 1 and type 2 diabetes are distinct because they arise from different origins. They are alike only insofar as they both lead to elevated blood glucose levels and concomitant “complications,” these physician-researchers stressed. A historical perspective on the characterization of diabetes can shed further light on how the differentiation of “types” of diabetes construes the origins of disease and the value of long, healthy human lives.

Using dogs as animal models, researchers at the University of Toronto discerned the role of insulin in humans in 1921. By the end of the first quarter of the twentieth century, insulin from pigs and cows became commercially available as a staple substitute for human insulin. For the first time, children and adolescents with type 1 diabetes could survive well into adulthood. Historians have documented the research that led to the commercialization of insulin and its impact on the first generation of people with type 1 diabetes to have access to this technology (Bliss 1982; Feudtner 1995). Historians have paid far less attention to research on and the treatment of the most common form of diabetes, type 2 diabetes (but see Marks 1997 and, less explicitly; Sinding 1999). To trace how “types” of diabetes have been characterized in biomedicine and in the scholarly medical traditions that preceded and informed it, I have relied mainly on an

encyclopedia entry in *The Cambridge World History of Human Disease* (Lieberman 1993).

“Diabetes” comes from a Greek word meaning “to run through” or siphon. For the Ancient Greeks, the hallmark of the disease was that food runs through the body instead of fuelling it, causing the flesh to melt down into urine. Ayurvedic physicians also recognized the clinical symptoms of diabetes, and attributed them to dietary indiscretion.

“Diabetes mellitus” is currently distinguished from a rare condition called “diabetes insipidus” in which sweet blood does not occur. The distinction between diabetes mellitus and diabetes insipidus derives from the historical practice, dating back to Ancient Greece, of diagnosing diabetes by the prodigious amount of urine produced. In the early 1700s, a physician noted the sweet taste of the urine produced by most, but not all, diabetics, giving rise to this distinction between diabetes mellitus and diabetes insipidus (Mintz 1985, 106, 247).

“Mellitus” is Latin for honey and “insipidus” is Latin for lacking flavour or taste.

Extreme thirst and heavy urination characterize diabetes insipidus. Today it is known that the hormone involved in diabetes insipidus is not insulin, but rather ADH (antidiuretic hormone), which regulates the amount of urine produced. The *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada* do not mention diabetes insipidus. They refer either to diabetes mellitus or simply to diabetes.

Until the 1950s, it was impossible to distinguish the sweetening of blood due to an absolute absence of insulin (type 1 diabetes) from the sweetening of blood due to insulin resistance or a relative lack of insulin (type 2 diabetes). As early as 1875, however, academic physicians recognized two clinical syndromes of diabetes mellitus. Patients with the first type were relatively young, and often included children; weight loss was marked; the onset was acute, and death quickly followed. Patients with the second type tended to be older, usually adults; they were often overweight; onset was slower, and they lived much longer. In the late 1800s, a type of diabetes present only for the duration of pregnancy was also

noted, but the term “gestational diabetes” did not appear in the English-language medical literature until the 1940s.

In the early 1950s, with technical improvements in the ability to measure the amount of a substance in a biological sample (bioassays), it became possible to measure the amount of insulin in a person’s body. People with diabetes could be “typed” according to the sweetness of their blood, but also according to how much insulin contained in their blood. These measurements showed that patients with the first clinical presentation of lifelong diabetes (currently known as type 1) produced no insulin at all, while patients with the second presentation (currently known as type 2) produced varying amounts of insulin.

Attempts to standardize definitions, nomenclature and diagnostic criteria around the world began in earnest in 1952, when the International Diabetes Federation held its first conference. Almost thirty years later, in 1980, global consensus on classification and diagnosis of diabetes mellitus was reached for the first time under the aegis of the World Health Organization. As discussed in this chapter and in the previous chapter, this consensus was considered obsolete by the late 1990s.

### **MEANS FOR UNSWEETENING BLOOD**

To sum up, biomedicine conceives the human body as a series of inter-related parts, such that biomedical research and related clinical practices seek to detect pathological features and identify their origins. Just as Melanesians (and “Westerners”) reckon the status of people by tracing the origins of gifts, the search for the origins of sweet blood cements the value of long and healthy human lives. A sample of blood may be used to “type” people based on the amount of glucose or insulin that it contains. These chemical traces index people’s social identities (type 1 diabetic, for example) and future prospects. Biomedical research has investigated how blood becomes sickly sweet in bodies; biomedical treatments seek to alter these “pathways” for the benefit of persons.

The history of the biomedical understanding of diabetes underscores the importance of statistical technologies. Changes in the understanding of diabetes reflect the desire to classify correctly, the better to intervene effectively. Since the rise of biomedicine in the mid-nineteenth century, the capacity to measure bodily states and properties has increased, and along with it, the capacity to “type” people and treat their afflictions. Notably, the capacity to measure the sweetness of blood, together with the over-riding concern with extending and improving lives, underwrote the experiments that led to the commercialization of insulin (see Bliss 1982). The capacity to measure the amount of insulin in the bloodstream has also proved significant in defining and understanding diabetes, offering a quantitative way of differentiating between the two main clinical presentations of diabetes. Moreover, the measurement of insulin quotients stimulated research into why some people (type 1 diabetics) lack insulin altogether, while others (type 2 diabetics) produce varying quantities of insulin yet register elevated blood sugar levels.

Through the “typing” sweet blood under the auspices of biomedicine, metabolic similarities among *some* humans and between humans and certain animals have acquired utility. Dogs were used to study the role of insulin in regulating blood glucose levels, while pigs and cows have been used as sources for commercial insulin. Dr Gerstein evokes cows, sheep, swine, horses, dogs, alligators, and octopuses to suggest that elevated blood glucose levels “are somehow bad for you, biologically,” departing as they do from cross-species norms effected by and conserved through evolution.

“Twentieth century Euro-Americans...do not like to imagine themselves as commodifying people” (Strathern 1996, 518), but “we” do, at the very least, routinely commodify human bodies, bodily capacities, and parts with biomedical concepts and practices that codify, compare, and evaluate lives. Similarly, biomedical researchers may value other, “lower” organisms for their ability to mimic and heuristically substitute for human bodies.

Researchers are currently working to “type” human and nonhuman beings more finely with a view to curbing or even curing sweet blood. To continue the examination of how biomedical research valorizes long, healthy human lives, the next chapter will analyze genetic knowledge about the origins of sweet blood.

## 5. Figuring Out Diabetes, Likening Bodies and Genes

Over the past fifteen years, genetic explanations for disease have come to the fore. Social scientists have followed “the new genetics” with great interest, and sometimes alarm. It has been suggested that the modern-day emphasis on genetics may redefine identities, revive eugenics, and overshadow the toll that social relations and conditions take on health and well-being (Flower and Heath 1993; Lippman 1991; Strathern 1995; Rabinow 1992; Rapp 1995; Petersen 1998, for example).

The ascendance of genetic explanations for sickness is heavily indebted to PCR (for polymerase chain reaction), a cloning technique that can be used, in effect, to magnify parts of the genotype. Using PCR, researchers can generate plenty from a scant amount of genetic material. Before the invention of this technique in the 1980s, genetic material derived from a particular biological sample was very finite. Afterwards, biological samples became an abundant, renewable resource in genetic science (see Rabinow 1996), greatly increasing the capacity to characterize genetic “parts,” and to create new populations based on genetic similarities and differences.

Diabetes research has hardly been exempt from the genetics research trend. Recent genetic research both reinforces and departs from current clinical understandings of sweet blood. Nevertheless, a recent qualitative study downplays diversity in biomedical knowledge about sweet blood (see Sunday, Eyles, and Upshur 2000). In regrouping their interview data into “two divergent causal stories,” the authors overstate the dissonance between how Aboriginal community members and health professionals described to them the origins of sweet blood. They attribute a unified epistemology to biomedicine, “with health being defined as a physical state.” By contrast, they report, “Aboriginal narratives emphasize the role of genetics in causation,” but also the ravages of colonization, thus stressing collective difference and experience over individual behaviour. This contrast

glosses over the biomedical roots of genetic explanations for type 2 diabetes. In allowing their sample of health professionals to speak for the entire enterprise of biomedicine, they cling to a truism, common among social scientists who conduct research on health and perceptions of illness, that there is a single “biomedical model” of the human body. They also neglect the implications of suggesting that an Aboriginal “holistic definition of health” fairly embraces genetic explanations for disease, which are often held to push biomedical reductionism to new extremes (see Lippman 1991; McDermott 1998, for example).

This chapter lends nuance to the portrayal of biomedicine and “the new genetics” in the social science literature by applying theoretical insights advanced to account for cross-cultural variation in how people construe the origins of sickness and other misfortunes. My anthropological analysis of biomedical theories expressly takes variation among biomedical theories and practices into account. Revisiting anthropological theory about causation, particularly as regards sickness, underscores that people may entertain different ideas about *how* something happened and *why* it happened. In anthropology, witchcraft provides the classic illustration of the difference between theories about how and why misfortune occurs (see Evans-Pritchard 1976 {1937}, especially chapter 2). For example, a group of people may accept that micro-organisms can incite sickness by invading human bodies, while invoking witchcraft to explain the pattern of victimization (Farmer 1992). Through the idiom of witchcraft, they attribute the ultimate origin of misfortune to the malevolence of others. Applying the distinction between how and why misfortune occurs to the case at hand highlights that, in biomedicine, clinical practice focuses on *how* blood sweetens in individual bodies, while researchers focus on *why* blood sweetens in populations. Concomitantly, by marshalling anthropological insights about variability in defining the boundaries of bodies, it becomes apparent that physiology construes human bodies as discrete spheres, but not genetics.

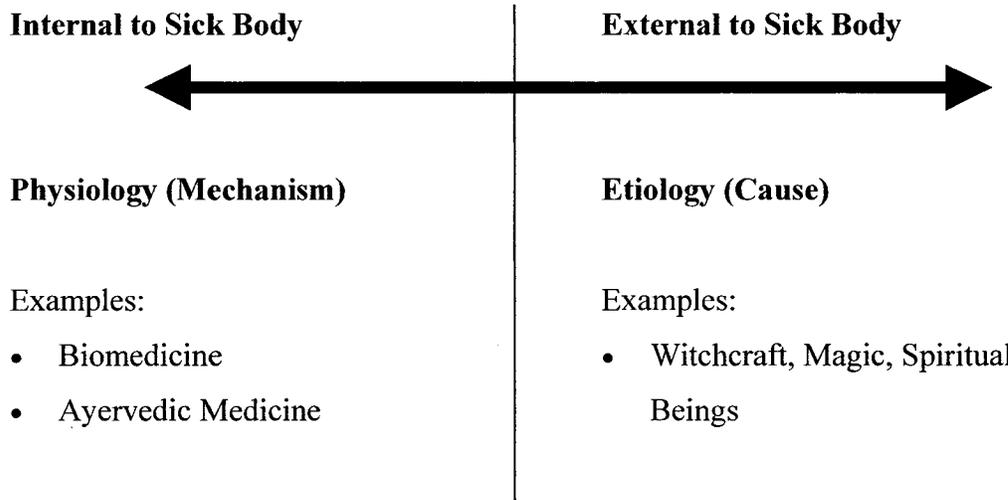
## THEORETICAL NOTES AND QUERIES

Allan Young's efforts to theorize how medical systems differ from one another have inspired my analysis of genetic research on sweet blood (see Young 1976). Young observes that medical systems vary in the extent to which significant events take place inside, not outside, the sick person's body (see Figure 14). *Internalizing* systems tend to rely on physiological explanations, in which images and analogies are used to model events within the sick person's body. *Externalizing* systems tend to rely on etiological explanations that identify a point in time before which it is unnecessary to search for the causes of a sickness episode. While both physiological and etiological explanations concern the origins of sickness, Young notes that physiological explanations focus on the mechanisms involved, but etiological explanations focus on what are perceived as root causes. Internalizing systems give rise to remedies targeting the inner physical state of the sick body; but externalizing systems tend to suggest actions designed to alter relationships embedding the sick person.

Young asserts that most medical systems found the world over and throughout history have occupied a middle ground between the externalizing and internalizing extremes. He also contends that internalizing, mechanistic accounts of sickness tend to predominate in large, structurally-complex societies. Further, both internalizing and externalizing explanations may be proposed during a given sickness episode, which provides the basis for pluralistic medical systems that feature explanations and treatments deriving from more than one epistemological tradition.

Young's taxonomy can be fruitfully compared to another approach to distinguishing medical systems published in the same year, 1976, which suggests that non-Western medical systems vary in the extent to which they invoke personalistic versus naturalistic causes (Foster 1998 {1976}). George Foster's understanding of personalistic medical systems closely resembles externalizing systems described by Young. Foster describes personalistic medical systems as follows:

**Figure 14:**  
**Origins of sickness**



(adapted from Young 1976)

A personalistic medical system is one in which disease is explained as due to the *active, purposeful intervention of an agent*, who may be human (a witch or sorcerer), nonhuman (a ghost, an ancestor, an evil spirit), or supernatural (a deity or other very powerful being). The sick person literally is a victim, the object of aggression or punishment directed specifically against him. Personalistic causality leaves little room for accident or chance... (Foster 1998 {1976}, 112, emphasis in original)

Similarly, Young explains:

*Externalizing* systems concentrate on making etiological explanations for serious illness. Here, pathogenic agencies are usually purposive and often human or anthropomorphized. Diagnostic interests concentrate on discovering what events could have brought the sick person to the attention of the pathogenic agency (e.g. grudges repaid by witchcraft, ritual lapses punished by ancestral spirits) in order to identify the responsible category of pathogen, or, even, the responsible individual agent (e.g. witch *X*). Often only gross symptomatic distinctions are made, since the intrasomatic link between etiological events and sequences of biophysical signs is either ignored or not elaborated. (Young 1976, 148, emphasis in original)

These two accounts have much in common, but Young is at pains to situate the sick body in externalizing systems, while Foster focuses on the highly restricted place allocated to chance in personalistic systems.

Foster's characterization of naturalistic medical systems diverges significantly from Young's characterization of internalizing medical systems, although at first glance, they too appear similar. Foster writes:

In contrast to personalistic systems, naturalistic systems explain illness in impersonal, systematic terms. Disease is thought to stem, not from the machinations of an angry being, but rather

from such *natural forces or conditions* as cold, heat, winds, dampness, and, above all, by an upset in the balance of the basic body elements. In naturalistic systems, health conforms to an equilibrium model: when the humors, the yin and yang, or the Ayurvedic dosha are in the balance appropriate to the age and condition of the individual, in his natural and social environment, health results. Causality concepts explain or account for the upsets in this balance that trigger illness. (Foster 1998 {1976}, 112, emphasis in original)

Here is how Young characterizes internalizing systems:

In internalizing systems physiological explanations are indispensable for organizing medical strategies. Even though etiological information is sometimes diagnostically important, diagnosis ultimately rests on the healer's ability to interpret symptoms whose form and place in the sequence of symptoms are explained physiologically. Similarly, although therapeutic success sometimes requires the neutralization of introjected pathogens, in the end, it depends on the healer's ability to restore physiological equilibrium. Typically, the physiological explanations are rationed by a particular theory or set of theories, and emphasis is given to systemizing medical beliefs in more than post hoc and pragmatic contexts. Western medicine, which is one instance of this type (and extends the characteristic explanation to even 'psychogenic' ailments by means of an equilibrium metaphor derived historically from a physiological context), is distinguished from examples such as Ayurvedic and Unani medicine because it concentrates on micro-level processes organized according to highly elaborated machine models.

(Young 1976, 148)

Crucially, Young explicitly theorizes biomedicine, but Foster excludes biomedicine from scrutiny.

Foster implies that *bona fide* disease (that is, sickness recognized by biomedicine) arise from nature. Foster therefore calls for anthropologists of

medical systems to account for the extent to which non-Western medical systems mirror biomedicine. More specifically, Foster contends that non-Western medical systems approximate biomedicine to the extent that “natural” causes, including chance, are thought to prevail. If non-Western epistemologies about sickness align with biomedical theories, they exhibit rationality and derive from universal truths. Indeed, Foster regards “man’s ability to depersonalize causality, in all spheres of thought, including illness, as a major step forward in the evolution of culture” (Foster 1998 {1976}, 113).

For Young, however, biomedical disease categories have a “social” as well as a “natural” existence. Young regards biomedicine, along with all other medical systems, as dependent on categories and devices. Foster’s typology largely reproduces the nature/culture dualism derived from the Western philosophical tradition, but Young seeks to socialize both “natural” and “cultural” explanations for the origins of disease. In doing so, Young distinguishes between causes (construed as external to human bodies) from mechanisms (understood to operate within human bodies). By contrast, Foster conflates mechanisms with “immediate, instrumental or technical causes.” Accordingly, he ultimately regards chance as a natural law (Foster 1998 {1976}, 114).

My research calls into question the notion that biomedicine anchors the internalizing end of a continuum stretching towards externalizing explanations. Biomedical research, I will argue, gives rise to externalizing explanations. Externalizing explanations in biomedical research encompass socially-structured environments, unintended consequences, and bodily states deemed to have developed at random; but externalizing explanations in other medical systems rely on purposive agents.

### **GENOTYPING DIABETICS**

Genetic accounts of diabetes offer greater precision in accounting for why certain people develop sweet blood than physiological descriptions or clinical clustering, but they have also fragmented taxonomies. Increasingly, as a geneticist

interviewed for this project put it, the characterization of disease evokes “intrinsic causes” rather than symptoms. This trend implies that “at the end of the 20th century ... disease has not gone away. But we have different diseases.” It used to be that “everybody who got polio had something that was fitted into a simple class: poliomyelitis. Paralytic or nonparalytic.... But now, when you're talking about diabetes, you have to ask: what type of diabetes?” He continued: “So my guess is that medicine is going to get tougher to practice because you will have individuality of disease [with] the genome of the individual conferring the susceptibility, conferring a condition which has a particular diagnostic element, and a particular requirement for treatment.”

Note the evocation of “susceptibility.” While contemporary geneticists strive to identify the determinants of disease, they do not regard one’s genetic endowment as the ultimate cause of disease in every case. Their mantra is “genotype plus environment equals phenotype,” where “genotype” is the genetic endowment of the body, “phenotype” encompasses all the observable features of a body, and the “environment” refers to everything with which a given body has interacted since birth.

Below I will examine the implications of this way of conceptualizing human bodies. My research indicates that genetic researchers still root the disease in the phenotype, even as they seek to identify origins in the genotype. In other words, a shared phenotype (sickly sweet blood) groups together people under a single category, “diabetes,” even as genetic research pulls apart this category to form various sub-populations. Given the concerns about genetic determinism raised by many social commentators (Lippman 1993; Nelkin and Tancredi 1992, for example), I was surprised to learn of the extent to which contemporary genetic knowledge attribute sickly sweet blood to “the environment.” Genes appear as necessary but insufficient causes for sweet blood in these accounts.

### *The Genetic Bases of Diabetes*

On October 13, 2000, at the Canadian Diabetes Association Professional Conference held in Halifax, Nova Scotia, Dr Morris Birnbaum of the University of Pennsylvania gave a plenary lecture. It was entitled, “The Search for Diabetes Genes: Where Have We Been and Where Are We Going?” His audience was made up of some 1,700 researchers, physicians, nurses, dieticians, social workers, and pharmacists. In introducing his presentation, Dr Birnbaum outlined two assumptions:

In the first case, it would be presumptuous of me to take any time to tell you about the importance of diabetes, as a disease, in Canada, the United States and the world. So I will take it that all of you understand the prevalence of the disease, the rising prevalence of the disease, the major clinical features and understand why we *need* look for really novel and inventive ways of finding new cures.

The second thing that I’m not going to say at the beginning but will say a couple of words about as we go along, is the reason *why* we search for diabetes genes. That is to say, the evidence that diabetes *has* a genetic basis. Again, I take it that all of you, either in your research or your clinical practice, have been impressed with the clustering of diabetes in families. And although most of you have perhaps not looked at that *quantitatively*, and analyzed it in a very detailed way, it is that analysis that provides the *formal* proof for the genetic basis for diabetes.

Note his reliance on statistics combined with an appeal to clinical experience to justify genetic research on diabetes. It also bears noting that he describes diabetes as having *a* genetic basis. Yet in the main body of his presentation, he treated diabetes as “family” of diseases with various genetic *bases*. “What gene is associated with diabetes?” is question best avoided, Dr Birnbaum said. He explained:

We're better off asking, 'What gene is associated with muscle insulin resistance?' Because there might be one gene associated for muscle insulin resistance, another gene responsible for liver, or another gene responsible for what goes on in the pancreas.

My purpose in pointing out this elision (genetic *basis* versus *bases*) is to underscore how research on diabetes simultaneously splinters *and* repairs the category "diabetes" as a meaningful way to "type" people. On the one hand, in the singular, the category "diabetes" refers to a common phenotype defined by blood sufficiently sweet to correlate statistically with such "complications" as eye disease, kidney disease, cardiovascular disease, and, overall, reduced life expectancy. On the other hand, "typing" people with diabetes more finely in terms of physiological processes and genetic characteristics underscores that sweet blood may stem from diverse origins, which may have clinical relevance.

### TYPES OF TYPE 1

Dr Birnbaum mainly presented genetic findings pertinent to type 2 diabetes in his lecture. In doing so, he frequently compared and contrasted type 2 diabetes with type 1 diabetes. Like type 2 diabetes, he explained, type 1 diabetes is genetically complex, meaning that no one gene triggers the onset of the disease. Yet type 1 diabetes illustrates complex inheritance more clearly than type 2 diabetes because far fewer genes seem to play a role in triggering type 1, Dr Birnbaum observed. Midway through his presentation, he noted that "the classic definition" of "a genetic disease is that the prevalence in siblings of affected individuals is greater than the general population." He continued, "Now this is much more obvious for type 1" than for type 2. Only 0.4% of the members of the general population have type 1 diabetes, but on average, "the risk to a sibling is 6[%], so [the] overall genetic contribution we say is 15%" because 0.04 multiplied by 15 equals 0.6.

Dr Birnbaum's illustrative use of type 1 diabetes to explain genetic principles to non-specialists is commonplace. In the upper-year survey course in human genetics that I audited, references to type 1 diabetes were commonplace.

In fact, on one occasion, a geneticist said that he would skip type 1 diabetes – “I think you’ve had enough of type 1 diabetes,” he said – to illustrate the utility of a technique in genetic epidemiology known as “linkage disequilibrium.” In any case, the textbook explained this technique with reference to type 1 diabetes. Linkage disequilibrium compares the expected and observed frequency of genes at specific locations to ascertain whether they contribute to the onset of disease.

Below, I summarize the current consensus within biomedicine about the genetics of type diabetes. This summary draws mainly upon lectures, notes and assigned readings for the human genetics class, supplemented by interviews and by entries for diabetes in the *The Encyclopedia of Human Biology* (Barzilai and Shamoon 1997) and *The Cambridge World History of Human Disease* (Lieberman 1993).

In the early 1980s, researchers found that people with type 1 diabetes tend to have certain combinations of genes in the “major histocompatibility complex,” which regulates the immune system. Type 1 diabetes sets in after the body’s immune system targets and destroys the insulin-producing cells in the pancreas. This process is most likely to occur among people with certain combinations of genes in the histocompatibility complex. In a small minority of people with type 1 diabetes, insulin-producing beta cells cease insulin production for reasons, still under study, unrelated to an autoimmune response.

Groupings of histocompatibility genes, known as haplotypes, are currently used to make fine-grained distinctions between people with type 1 diabetes. Researchers identified these haplotypes using statistical analyses, which found that certain genes tend to appear together on the part of the genome that helps regulate the composition of the immune system cells. Different haplotypes are associated with the onset of type 1 diabetes to varying degrees. The majority of persons with haplotypes conferring susceptibility for type 1 diabetes do not develop the condition.

Certain haplotypes have clinical significance besides conferring genetic susceptibility for conditions such as type 1 diabetes. For example, kidney donors

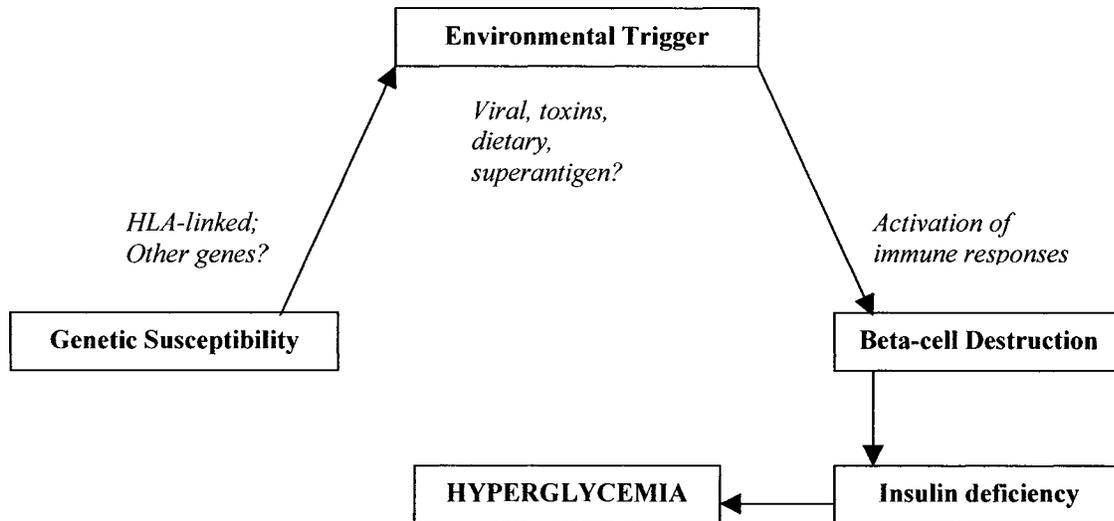
and recipients are usually matched by human leukocytic antigens (HLA), conceived as products of histocompatibility genes (see Hogle 2000 for discussion). Members of the transplant team whose staff meetings I observed as part of my fieldwork gathered, relayed, and discussed “what genetics said” – that is, the results from histocompatibility testing – before scheduling surgery.

Among identical twins, after one twin develops type 1 diabetes, the other twin develops the disease only 35% of the time, underscoring the significance of “environmental factors” in the onset of this condition. Numerous epidemiological studies have examined the role of viruses, other infectious diseases, and nutrition (such as being fed cow’s milk as an infant) as triggers for type 1 diabetes, but without definitive results. Still, type 1 diabetes is generally more prevalent in urban populations, suggesting that urbanization increases the risk of exposure to precipitating environmental conditions. Figure 15 illustrates the current consensus on the role of genes, “the environment,” and the immune system in the development of type 1 diabetes.

The major histocompatibility complex that plays such a significant role in genetic susceptibility to type 1 diabetes is not exclusive to human beings. In fact, this complex is found in all mammals. It first came to scientific attention in the 1930s with the initiation of research on organ transplants using mice. “There’s a lot of ancient history in there,” underscored a geneticist who taught the human genetics class that I audited as part of my fieldwork.

Histocompatibility genes mediate the human body’s recognition of itself as a unique physical entity. In evolutionary and thus genetic terms, this capacity is not unique: all human bodies along with all other mammals depend on their respective histocompatibility complexes to distinguish self from other. Genes found in the histocompatibility complexes of humans and related animals do not directly or inevitably cause type 1 diabetes. Instead, certain combinations of histocompatibility genes increase the likelihood of developing type 1 diabetes. Put another way, genetic endowment serves as a basis for defining populations at higher risk for type 1 diabetes.

**Figure 15:**  
**Genetic and environmental factors**  
**in the onset of type 1 diabetes**



Adapted from: (Barzilai, 1997, 265)

## TYPES OF TYPE 2

After invoking type 1 diabetes to illustrate complex inheritance, Dr Birnbaum outlined some methodological challenges in genetic research on type 2 diabetes that do not arise when conducting corresponding research on type 1 diabetes. Unlike type 1 diabetes, no single region of the genome has been tied to most cases of type 2 diabetes. Instead, any number of problems may arise along “the metabolic pathway” in type 2 diabetes, and these various metabolic problems may stem from any number of gene combinations. Additional challenges arise because type 2 diabetes usually develops much later in the life than type 1 diabetes. Dr Birnbaum explained:

When you're dealing with a disease which people get late in life, doing these genetic studies can be very, very difficult, because how many generations could you really get back? Think to yourselves, how many of your patients can you ask, 'Does your grandfather have diabetes and will he come in to donate blood?' [some laughter from audience] You know. It's difficult.

In addition, Dr Birnbaum explained, genetic researchers cannot be sure that siblings or even parents of people with type 2 diabetes will not ultimately develop the condition themselves because type 2 diabetes tends to develop in mid-life or later.

The bulk of his presentation consisted of examples of the methodological strategies employed by researchers to overcome these challenges, and the results that they have yielded.

### *From Mexican-American Families to Calpain-10 ... to Diabetes?*

Dr Birnbaum reported that geneticists often employ “affected sib-pair analysis” to circumvent the challenges inherent to researching type 2 and other adult-onset conditions:

Affected sib pairs only looks at siblings who have the disease.  
And it's based on the following principle: that if two siblings

have the disease, they're more likely to have the same gene at the region that is causing the disease.

Using sib-pair analysis, which involves comparing the extent to which siblings who both exhibit the condition of interest resemble one another in genetic terms, researchers aim to distil the origins of disease.

To illustrate the utility of this methodology, Dr Birnbaum described results from research on type 2 diabetes in a "Mexican-American" population:

Anyway, Graeme Bell and his colleagues at the University of Chicago over the last 10 or 15 years have been doing a study just like this.... And through a very convoluted genetic argument that I couldn't, I couldn't explain now if I wanted to, they've really come up with the idea that a specific gene called calpain-10 is associated with diabetes in this population.

He explained that calpain is an enzyme that helps break proteins down into smaller parts. The research entailed scanning the genomes of the study subjects – "cloning out hundreds, I mean literally millions of base pairs of genes" – to identify tiny parts of the genome (single nucleotide polymorphisms, or SNPs) "which track with diabetes."

But most importantly, before Graeme Bell identified this gene, there was *no reason* in the world to suspect that this protein had anything to do with diabetes. And this is the strength of this approach. If this is right. And I still caution you that this is still very, very controversial. Not because of poor quality science on Graeme's part, but because it's *so hard* to prove a specific gene.

Thus, Dr Birnbaum underscored the laborious nature of this kind of research into type 2 diabetes, but also its potential for generating new hypotheses about the origins of type 2 diabetes (see also Nature Genetics 2000). To understand type 2 diabetes better, Dr Bell and allied researchers regrouped immediate kin (siblings) to define a lineage endowed with a particular gene that predisposes to sweet blood. They have imputed the origins of the sweet blood flowing through a particular group of "Mexican-Americans" in long-dead ancestors. In the process,

they extend the politics of race and ramify the politics of nationhood (see Montoya 2001 for further discussion).

### ***MODY: When Diabetes is an Unequivocal Inheritance***

MODY (for “maturity onset diabetes of the young”) is another kind of diabetes discussed by Dr Birnbaum. Indeed, he described several MODY forms, all of which present clinically as type 2 diabetes. He also indicated that MODY forms could account for a significant proportion of type 2 diabetes: “Conservatively, it’s at least 5%” and in some populations, this figure may reach 20%, Dr Birnbaum said. Currently, treatment recommendations do not differ significantly for these forms compared with “garden variety” type 2 diabetes. “So right now it’s not a major problem that you might not be able to distinguish these patients,” Dr Birnbaum said.

MODY forms invariably involve autosomal dominant inheritance: “You have a 50% chance of getting it from an affected mother or father.” That is, unlike type 1 and “garden variety” type 2 diabetes, MODY forms of diabetes are *not* genetically complex. Instead, a single gene codes for sweet blood: “If you have the gene, you almost invariably get the disease.”

The *1998 Clinical Practice Guidelines for the Treatment of Diabetes in Canada* recommend that the designation “genetic defects of beta cell function” should replace the “MODY” terminology (see Meltzer et al. 1998), but as illustrated by Dr Birnbaum’s presentation, “MODY” remains current. The *1998 Clinical Practice Guidelines for the Treatment of Diabetes in Canada* also distinguish these forms from type 2 diabetes. Dr Birnbaum and many others working in the field sometimes refer to MODY forms as exotic strains of type 2 diabetes, and sometimes they contrast MODY with type 2 diabetes.

Dr Birnbaum illustrated heterogeneity among MODY forms by profiling research carried out by two of his colleagues at the University of Pennsylvania.

Geneticists were able to show that a region of chromosome 7 contained what would become known as MODY-2 gene, but they could narrow it down no

further, recounted Dr Birnbaum, so they drew upon physiological expertise: “Franz Matschinsky at my institution, the University of Pennsylvania, has argued for 25 years that glucokinase is the protein that is the key to insulin secretion.” Chromosome 7 contains the gene that regulates the production of glucokinase, a protein (more specifically, an enzyme) that stimulates insulin secretion. With the help of glucokinase, the cells in the pancreas convert glucose into insulin. Dr Birnbaum observed that it was simple to ask if an abnormal glucokinase gene could cause the disease. “In fact, I wouldn't be telling you this story if the answer wasn't yes,” he said.

A particular mutation in the glucokinase gene was found to trigger the onset of MODY-2 (see Burke et al. 1999), which has distinct clinical features:

You get hyperglycemia early in childhood....even before [age] ten. The hyperglycemia is mild, and it doesn't really change with age. Where you are early in life tends to be where you're going to be when you're grown up. There's very little in the way of complications. It's unclear right now whether there's any reason to treat this disease. The glucose is up, but it's a mild hyperglycemia.

Dr Birnbaum contrasted this almost benign genotype with MODY-4, which has much more serious clinical implications.

When another colleague encountered a baby born without a pancreas, it was already known from experiments on mice that inheriting two copies of the gene PDX results a congenital absence of a pancreas. Dr Birnbaum recalled:

Well, Doris Stoffers,, in looking very carefully at the relatives of this [baby], noticed something very interesting. She noticed that the father of this [baby born without a pancreas] had diabetes. No big deal, it's a common disease. But even though he had what looked like type 2 diabetes, he developed it when he was 17 years old. OK. And she couldn't find any evidence of an immune response, indicating this wasn't type 1 diabetes. 17 years old with type 2 diabetes, OK. So she looked at the larger family and developed a pedigree, and looked at all of the

individuals in the family who developed diabetes at an early age.

The pedigree showed that about half of the baby's paternal *and* maternal relatives developed what looked to be type 2 diabetes in early adulthood, and they all had a copy of the PDX gene (see Stoffers et al. 1997). MODY-4 tends to develop during late adolescence or early adulthood – generally before 35 years of age. “But it's clearly very different from garden variety type 2 diabetes” because it is associated with a specific gene, Dr Birnbaum emphasized. Furthermore, babies who inherit two copies of the gene are born without a pancreas.

The differences between MODY-2 and MODY-4 illustrate that the various MODY forms differ from another by both genotype and clinical archetype. People with the same MODY form, whether or not they belong to the same immediate family, share genetic substance and have similar “life chances.” Unlike type 1 diabetes and “garden variety” type 2 diabetes, all MODY forms stem from the inheritance of a single gene that, in time, induces sweet blood, no matter the surrounding environment. The moment of conception determines whether or not a person will eventually develop a MODY form of diabetes. Further, as with other genotypes linked to diabetes, people with MODY-inducing genes may share substance with nonhuman beings (cf. Strathern 1996), to the point that their fates intertwine with those of certain “lower” relatives. Humans *and* mice with two copies of the gene linked to MODY-4, for example, will die soon after birth in the absence of remedies to compensate for the absence of a pancreas.

### ***Extrapolating from “The Current Dogma”***

Contemporary genetic research may begin with affected people, as with the research that linked calpain-10 to type 2 diabetes, but it often “start[s] from the biology,” explained Dr Birnbaum. As illustrated above, expertise about “normal” physiology was instrumental in the characterization of the abnormal glucokinase gene linked to MODY-2.

Dr Birnbaum summed up “the current dogma” about the physiology of type 2 diabetes as follows:

So in type 2 diabetes, we have three defects: an inability of the pancreas to respond appropriately to the glucose; an inability of the liver to stop making it; and an inability of the muscle to take it up appropriately.

Dr Birnbaum then presented physiologically-driven genetic research from his laboratory, which has been designed to explain why people with type 2 diabetes so often fail to produce adequate amounts of insulin.

The goal of this research is to ascertain whether a “normal protein” known as AKT plays a role in the onset of diabetes. Dr Birnbaum and his team found that the mice programmed to over-express AKT ended up with eight to ten times more insulin-producing cells than the normal controls. Further, Dr Birnbaum and his team found that these mice did not develop diabetes even after being injected with a toxin that usually kills the insulin-producing cells. “We've completely prevented diabetes in these mice,” Dr Birnbaum underlined. The over-expression of AKT is not a practical therapy for human beings, however, because the mice ultimately develop “other problems due to an abnormal expression and large quantities of a protein.”

Here mice stand in for some of their “higher relatives,” human beings with type 2 diabetes. This research strategically collapses *and* exploits the “evolutionary distance” between mice and human beings. Through the measurement of physiological features and the manipulation of associated genetic properties (the amount of AKT and the genes that regulate its expression), they compare mice and people with type 2 diabetes. By experimenting on mice, the researchers certainly have a greater range of techniques at their disposal: they compromise and sacrifice the lives of the mice in research because they hope that, ultimately, their work will extend and improve human lives.

### ***Of Genes and Volition***

Dr Birnbaum repeatedly emphasized that one of the main advantages of genetic research is that it may help researchers explore pathways that have never been thought to play a role in the onset of diabetes. This theme can certainly be

seen in his summary, cited above, of the research that linked calpain-10 to the sweetening of blood among a group of Mexican-Americans.

In another example, this one drawn from some ongoing research in his laboratory, Dr Birnbaum explained that depriving mice of a certain enzyme by “taking a very specific gene, and [introducing] a very modest modification” reduced the desire to exercise:

What we’ve done here is we’ve taken mice, normal mice and mice which are deficient in this critical enzyme AMP-K in the muscle and the heart. And we’ve put them in a cage, put them in their cages, and we’ve put exercise wheels in the cages. Now we did not force them exercise. We’ve simply given them the opportunity to exercise.

Audience members laughed uproariously, prompting Dr Birnbaum to say, “You’re way ahead of me here. I was going to draw the obvious analogies; I’m delighted you’re getting them long before I have to tell them to you.” He underscored that this experiment illustrates how hard it is to predict which genes are involved in diabetes:

You can have a gene somewhere, which in your brain or in this case in your muscle in some very strange and confusing way may influence your desire to exercise, your ability to exercise. It wouldn’t ever appear in our classic pathways of insulin action. And yet as we all know from our practices, it would predispose that individual to [type 2] diabetes. And that’s what we’re very excited about in this gene. We showed in collaboration with Laurie Goodyear at the Joslin Institute that this gene is activated in human beings when they exercise. So we think that –So we know the model has relevance for human beings. And hopefully over the next couple of years, we’ll see whether this is disturbed in type 2 diabetics.

As with the previous example, this research uses mice to model the origins of type 2 diabetes in humans. In this case, the gene in question may affect volition in a population of humans as well as in kindred mice. Ultimately, as Dr Birnbaum

suggested and his audience clearly grasped, a tendency to eschew physical activity could contribute to the onset of type 2 diabetes among people “free” to determine how often and how long they exercise. Dr Birnbaum cautiously but confidently implied that evolution, through lines of biological descent, might root behaviour associated with type 2 diabetes in certain populations composed of human beings, as well as mice.

### ***Modelling Origins, Invoking Histories: Drosophila to the Rescue?***

Dr Birnbaum concluded his lecture by suggesting that the study of organisms “lower” still than mice may yield genes linked to the onset of type 2 diabetes in humans. To introduce this approach, he suggested what an ideal diabetes gene-hunting expedition might look like. He said that he would like to induce gene mutations in some 100,000 mice and then identify the ones that have acquired diabetes as a result of genetic manipulation:

We do a fasting glucose [test] on 100,000 mice, repeat it three times because it’s pretty variable, find the mice that have diabetes, and clone out the genes. Identify the region of the gene that causes the diabetes, and figure out what it is. I mean, that’d be a great experiment. We’d probably find a lot of diabetes genes that way.

He paused for dramatic effect, and then he broke some bad news: “That experiment is technologically, financially and emotionally impossible.” The audience roared with laughter. Dr Birnbaum continued, “I mean, none of us can *dream* of managing 100,000 mice.” The laughter, which had faded, resumed. “Now we’ve got to do 100,000, because it’s pointless to do this experiment unless we mutate most of their genes,” Dr Birnbaum said; otherwise, the likelihood of inducing a genetic mutation that is pertinent to the development of diabetes in humans remains too low.

Next he introduced that most convenient of laboratory creatures, the venerable *Drosophila*, as a possible key to the genetic origins of diabetes in human beings:

On the other hand, there are organisms you can do that with. I'm just going to repeat: there are organisms with which scientists do that all the time. Yeast. Fruit flies are the classic organism, where you can mutate a fruit fly and screen 100,000 for ones that are missing wings, or have an extra eye, or, you know, do stuff that you look at under a microscope in 10 seconds.

The only problem, Dr Birnbaum indicated, is being sure that the findings have relevance for human beings. After all, the bodies of human beings and flies differ dramatically today because their evolutionary histories diverged millions ago. Still, Dr Birnbaum argued that fruit flies sufficiently resemble human beings to derive useful information from their study about the origins of sweet blood in human beings. Human beings, mice, *Drosophila*, and all other animals feature an "insulin signalling pathway," and this commonality is what may permit fruit flies to stand in for human beings in genetic research on diabetes, Dr Birnbaum explained.

To demonstrate the viability of using fruit flies as model organisms in genetic research on type 2 diabetes, Dr Birnbaum described research in his own laboratory and in a Swiss laboratory. These experiments show that in *Drosophila*, the insulin-signalling pathway regulates the size of the cell, the size of the wing and the size of the fly itself. Many members of the audience laughed when Dr Birnbaum suggested, "Now that's parallel in some ways with human beings."

He continued:

I mean, if you just stop and pause for a second, and think about, you know, the fruit fly on your banana. And how unrelated he is to you. But to think that that fly uses insulin signalling in the same way you do. It uses that insulin pathway to tell it that there's plenty of food around....Insulin signalling *evolved* as a way of telling the organism that there's food around. What's changed a little bit in evolution is how the organism responds to the knowledge that there's a lot of food around. In a fly, it makes a bigger fly. In us, it takes the nutrients and converts it

into...glycogen or triglyceride, or protein. But fundamentally, the response is the same.

Does the response, the larger response still exist in human beings? Well I think all of you know the answer. Think about your patients. Think about your infants of diabetic mothers.

What's the single most impressive characteristic of those babies? Macrosomia. These babies are enormous. And they're not enormous just because they're storing more nutrients, no. They're enormous because the cells are larger. There's probably more cells also.

To wrap up this portion of his presentation, he said:

So we're very, very excited about this. Because now, we can take a fly with a large eye, a large eye because it has had an increase in insulin signalling. And induce a mutogenesis: make mutations in 100,000 of those flies, and simply by brushing them under a microscope in a course of a year – still a year's work, but that's not bad – in a year, we can find other mutations that make that eye bigger, make it smaller. And those will be mutants in other parts of the insulin-signalling pathway. Mutations in genes that we currently *don't* know about. And then once we know about those genes in the flies, we'll look at them in the human, and figure out whether they cause diabetes.

Sustained applause followed the conclusion Dr Birnbaum's lecture. After the applause died down, the chair of the session said, in awe:

Wow. That was an absolutely outstanding talk, and a brilliant example of deductive reasoning. And there are actually not many people around, let me tell you, there are not many people around who can take highly esoteric, very scientific work and make it understandable to all of us. In fact, there are probably only one or two people around who can do that, and we have one of them here. So thank you very, very much for that.

Yet more applause followed the chair's remarks.

What initially seemed preposterous to the audience – that researchers could exploit likeness between human beings and fruit flies to generate new knowledge about the origins of type 2 diabetes – seemed sensible by the end of Dr Birnbaum’s presentation. Accordingly, I argue that biomedical research redraws kinship lines to encompass humans who are strangers to one another as well as animals and even insects. Further, the valorization of human longevity and health provides the impetus for diabetes researchers to elaborate kin relations, the better to exploit both genetic similarities and differences. Within an evolutionary cosmology, the genetic characteristics of long-dead lineage founders, utter strangers, and even “lower” life forms help explain similarities and differences among immediate and distant biological relatives.

### *Thrifty Genes?*

To round out this chapter, I analyze a conference presentation by Dr Robert Hegele, an endocrinologist who has conducted genetic research on diabetes since 1985, one of his key publications, and press coverage of this publication. This analysis extends my observations about how genetic research transfigures kinship. It also brings my anthropological account of the political economy of knowledge about sweet blood to bear on a significant line of research in biological anthropology. This line of research posits that many, perhaps all, ancestors of people alive today oscillated between feast and famine (see Szathmary 1994 for review). Under such conditions, people endowed with “thrifty genes” that allowed them to derive maximum utility from their food would have the best chances of survival.

Dr Hegele was the final speaker in a session entitled “Diabetes in First Nations Communities: An Evolving Epidemic” which took place during the 1997 CDA Professional Conference, held in London, Ontario. Of the four speakers in this session, he alone focused on the genetics of diabetes. Specifically, he presented genetic research into the type 2 diabetes epidemic among residents of the Oji-Cree community of Sandy Lake in Northern Ontario. Genetic research is

one component of a community-wide project encompassing epidemiological research and prevention.

Dr Stewart Harris, co-principal investigator for the diabetes research program in Sandy Lake, chaired the session. In opening the session, he said, “To position this symposium on the first day of this, a national conference, I believe signifies the increasing appreciation of this major health issue facing our First Nations people.” Linda Brazeau, president of the National Aboriginal Diabetes Association (NADA), was the first speaker. Then Dr Bernie Zinman, introduced in chapter 3, presented an epidemiological portrait of Sandy Lake. Along with Dr Harris, Dr Zinman is a co-principal investigator for this project. Next, Dr Ann Macaulay presented results from diabetes-related research in the Mohawk community of Kahnawake. She was followed by Dr Hegele.

Before presenting any findings, Dr Hegele provided a primer on genetics. First he showed a slide with a photograph of Winston Churchill, who lived past his 91<sup>st</sup> birthday even though he exhibited many risk factors for metabolic and cardiovascular disease (stressful job, rich diet, heavy drinker, overweight, little physical activity). “One concept that I would like to impart to you today is that Churchill would represent somebody who...may have had a degree of genetic resistance to metabolic complications, to metabolic problems,” said Dr Hegele. He stressed that people do not inherit “a complex disease such as type 2 diabetes” in the same way that people inherit cystic fibrosis (an autosomal recessive disorder). He continued:

You inherit a background from both parents that sets a sort of fertile groundwork for the development in the future of diabetes. And the development, the final expression of the disease depends fundamentally on the environment. And in 12 years of doing research in human genetics, what I’m learning as I go on, is the fundamental role of the environment.

A couple of minutes later, he returned to the crucial role played by “the environment” in determining the sweetness of blood:

Our genetics, which we inherit from our parents, set the absolute biological limits for the expression for the phenotype. But our exact position within these limits – so the position of, say, blood sugar or the actual frank expression of diabetes – is determined by the environment.

Because “the environment” plays an integral role in the onset and progression of type 2 diabetes, Dr Hegele underscored that it *is* possible to extend and improve lives, and even prevent the development of type 2 diabetes in the first place:

So there are those people who incorrectly think that genetics is a fatalism, or a determinism, or a nihilism. So in other words, [some people think that] if you carry genes that render you susceptible to diabetes, you may as well forget about trying to do anything with the environment because you are in fact predestined. And in fact, this is the furthest thing from the truth.

To reiterate this important point, Dr Hegele emphasized that the onset and severity of diabetes depends heavily on factors *besides* genetic endowment. The disease does not rest in the genotype, therefore, but in the phenotype.

Dr Hegele envisioned two main clinical applications of research into the genetics of type 2 diabetes. First, using genetic screening, “we may identify individuals who are at particular risk and then intervene at a young age.” It may become possible to “tailor” such interventions to the individual, Dr Hegele suggested, so as to circumvent the onset of sweet blood and associated “complications.” Secondly, Dr Hegele explained that studying how genetic and physiological pathways interlace might lead to the development of new medications or other helpful innovations.

To study the genetics of sweet blood in Sandy Lake, Dr Hegele and his team asked, “What are the genes that are determining the increased susceptibility to diabetes in Sandy Lake, in the presence of the other factors that Dr Zinman mentioned, the inactivity and the caloric excess?” Thus, explained Dr Hegele, we “didn’t look at diabetes exclusively, [we] also looked at intermediate traits....we looked at plasma glucose, 2 hour PC [post-crandle, after eating] glucose, plasma

insulin.” The researchers did not confine their study to those with “frank diabetes” because, Dr Hegele reminded the assembled, the diagnosis of diabetes is made when the sweetness of blood exceeds a statistically-set threshold:

...the definition of diabetes is inextricably linked to plasma glucose. And plasma glucose is a quantitative trait that has a distribution in the population. So if the disease itself is defined by a threshold on a quantitative trait, then factors that determine levels of the trait could also be determinants of the disease.

Next Dr Hegele outlined some practical and theoretical issues in researching the genetics of the diabetes in Sandy Lake:

Because the population of Sandy Lake was started by a relatively small number of families, we know that the number of alleles predisposing to diabetes must have been very small. In fact, maybe several generations ago there may have been only one or two people who carried the predisposition to diabetes, and many more of their descendants living today after many generations are carrying the susceptibility, and that’s what Dr Zinman and Dr Harris have observed in the population. There’s an increased probability of finding recessive traits. That’s a point that’s of interest to a geneticist. There’s a homogenous gene pool, which reduces the complications of background genetic variation. If you imagine trying to do this study in downtown Toronto or London, Ontario or any sort of more cosmopolitan environment, there’s a tremendous amount of genetic background, which might obscure the small effect of a gene or trait. The other thing is that to a large extent these people have a shared environment. So they all live in the same climate, they shop in the same store. This reduces the complexity of trying to look at genetic determinants of a trait.

Note the recent vintage of genetic and then environmental changes that, Dr Hegele contends, currently underpin the diabetes epidemic in Sandy Lake.

Since the current population of Sandy Lake descended over a few generations from a handful of families who were quite isolated from other gene pools, Dr Hegele suggests that a predisposition to diabetes may date back only a few hundred years. Meanwhile, settlement and its accoutrements, including type 2 diabetes, have an even more recent history. Only fifty years ago, the “complications” of diabetes – blindness, kidney failure and cardiovascular disease – were virtually absent. Reflecting Canadian policies of the day, Sandy Lake residents’ ancestors began to settle year-round early in the twentieth century (Gittelsohn et al. 1996, 368). Currently, with unemployment averaging 80%, public assistance is the main source of cash income, which is supplemented by the sale of local crafts and by seasonal forays to hunt, fish, and trap (Gittelsohn et al. 1996, 368).

In referring to the fact that the residents obtain most of their foodstuffs from a single store, Dr Hegele implied that colonization has played a crucial role in converting susceptibility into the “frank expression” of diabetes. About forty minutes before, Dr Zinman’s presentation had explicitly linked colonization, the escalating type 2 diabetes problem, and the local store. Known as “the Northern,” the local store and others like it in remote communities descended from trading posts operated by the Hudson’s Bay Company, Canada’s oldest corporation and currently Canada’s largest department store chain. The ancestors of the residents of Sandy Lake likely began trading furs at Hudson’s Bay posts in the mid-1600s (Gittelsohn et al. 1996, 368).

Given the importance attributed by Dr Hegele to “the environment” in the diabetes epidemic in Sandy Lake, Dr Zinman’s description of residents’ routine reliance on “the Northern” bears quotation here:

This is the Northern. Your everyday value store. And indeed it is an everyday value store. No competition and the prices are very high. So it’s value, but it costs a lot. Notice that people are shopping, and also notice that everybody has a car. To walk in Sandy Lake would be unusual. You know, there must be something wrong with your car...

Consumption of lard in the community is extremely large. People do not associate eating high-fat foods with diabetes, and that is part of the education process. And I think this slide shows some good news, because in the old slide I had, the fruits and vegetables were down here and the lard was up here. So we have some progress. At least they're putting it in on lower shelves. Hopefully it will disappear from the community.

Now I had to show this slide, because it always gets the best response. This is Klik. Now, I've never eaten Klik, but I'm told it's a popular food in Sandy Lake. Klik is a canned meat. It contains some meat, mostly fat. It is put on bread, and it's a quick snack. Now there is something called Klik Lite, and Stewart [Harris] and Tony [Hanley, a PhD student supervised by Dr Zinman] and the rest of the people decided that they should change this to Klik Lite, which has far less calories. However, it wasn't selling. So the Northern said, 'Listen, we can't put things on the shelves if people are not going to buy.' So we did the Pepsi-Coke challenge test equivalent and we had a Klik – Klik Lite challenge. And indeed, nobody could identify Klik Lite as being different than Klik. And that started the process to allow people to then start using Klik Lite. Now there is something called Chicken Klik and that's even better than Klik Lite.

According to Dr Zinman, Dr Hegele has suggested, tongue in cheek, that Chicken Klik be re-named "Kluck."

In his presentation, Dr Hegele explained that the sweetness of blood in Sandy Lake is attributable to several genes and their aggregate effects against the backdrop of a predisposing environment. He also reported that progress had been made in pinpointing the genes that contribute to the problem:

So what we'd started at was looking at traits that were related to diabetes but not diabetes itself. So for example, body mass, we found a genetic determinant that was found in individuals in Sandy Lake who were a little bit fatter, whose body mass index

was about 10% above average.... There was a gene that tended to raise blood pressure in these people; there was a gene that – and Dr Zinman went over some of these factors, LDL [low density lipoprotein] cholesterol and triglycerides – there were genes that raised these within these people; and then finally this month, we've reported a genetic variant that seems to raise glucose. Although it does not predispose to diabetes, but once you have diabetes, if you have this gene, the blood sugar is higher, the phenotype is worse. So it's a modifier gene, but it's not the susceptibility gene for the diabetes.

The bulk of Dr Hegele's presentation elaborated on these research findings. I will highlight one line of research because it involves mitochondrial DNA. Given the features of mitochondrial DNA (Strachan and Read 1996 for an overview), this section of Dr Hegele's presentation further illuminates how biomedical research on the origins of diabetes interfaces with evolutionary theory about the origins of human beings.

The mitochondrion is the biological descendent of bacteria, researchers have found, and that is why it contains its own DNA. About 1.5-billion years ago, a very distant ancestor absorbed some bacteria into its very cellular structure. Since that time, the mitochondrion has evolved to metabolize energy in the cells of all complex organisms. Flies, human beings and all other animals possess a mitochondrion in each of their cells. In this sense, through the serial replication and transmission of mitochondrial DNA, human beings and all "lower" animals share substance with each other and with a particular strain of bacteria.

Mitochondrial DNA is implicated in how many Sandy Lake residents regulate their triglyceride levels (that is, the fattiness of their blood), reported Dr Hegele. But first he provided a description of the mitochondrion:

Normally when we think of genetic factors we imagine that we inherit half of our genome from our mom and half of our genome from our dad. And that's basically correct, except for one little tiny bit of DNA, which is the DNA which is in our mitochondria,

which are the little organelles which are important in our energy metabolism in the cell.... So it's DNA that's outside the nucleus. The egg, the ovocyte has 300,000 mitochondria. Poor little sperms only have fewer than 200 of those. And so in fact, all of our mitochondrial DNA that is now measurable within ourselves is basically determined by our mother's genotype. So what do we inherit from our mothers besides a life-long legacy of guilt? [laughter from the audience] It's in fact mitochondrial DNA.

He then outlined the "Eve hypothesis," which, based on the analysis of mitochondrial DNA, supposes that all human beings alive today are the biological descendants of a single woman who lived about 40,000 years ago.

"[W]e hypothesized that mitochondrial DNA variation would be associated with common phenotypes related to diabetes, in their energy metabolism," he then reported. Dr Hegele said that the structure of mitochondrial DNA among the residents of Sandy Lake does not predict the onset of type 2 diabetes, but it does predict triglyceride levels. Thus, variation in a body part found in all human beings and "lower" life forms marks certain residents of Sandy Lake as at higher risk for cardiovascular disease, a potentially-fatal "complication" of sweet blood. Further, this body part demarcates certain residents of Sandy Lake as members of particular matrilineage. Dr Hegele ended the section of his presentation by saying, "And again this actually was the first report in the world literature that I was aware of where any human trait was related to variation in mitochondrial DNA." (See Hegele et al. 1997 for details.)

Following his presentation, an audience member asked Dr Hegele to spell out the theoretical implications of his research:

Did what you tell us contribute to proving that the thrifty genotype theory is right? And I'd also like to know, do you agree with the thrifty genotype theory? Because I personally find it very useful as a way of explaining to people why diabetes is frequent in First Nations. I don't know if it's right, but it seems to make sense. The only thing it doesn't explain is why diabetes

isn't more common among Inuit people. Maybe they're protected somehow. Maybe they have good genes too.

In his reply, Dr Hegele provided an overview of the thrifty genotype hypothesis and explained why he endorses it:

That's an excellent point, and I realized that at the beginning of the talk I did want to mention the thrifty genotype. And I mentioned to Stewart [Harris] that I was going to talk about it. So I'm glad you brought it up now.

So the thrifty genotype was proposed in the 1960s by James Neel who is still living, still alive to see the fact that he really was quite prescient. [He died 1 February, 2000.] And the idea was that in an environment that was very harsh and calorically limited, that our physiology would evolve in such a way to treat every calorie as if it was gold – to preserve every calorie, and to become extremely economical in our basal metabolic rate and energy expenditure and this sort of thing. And that would help for survival in a harsh environment.

And then with the change in environment as has happened with First Nations people in the last 100 years, and even in the last 50 years, suddenly there is a glut, a surfeit of calories. The genetics and physiology has not yet caught up to the rapid change in the environment. Now all of a sudden, these calories which were treated so economically before now become in fact a detriment. And I'm personally a big believer in the thrifty genotype [hypothesis]. I'm not sure if these particular examples that I've shown would prove it, but I think that there's a lot of merit to it, both from these kinds of almost anecdotal observations in Native people but from other populations as well.

As suggested by the original question and Dr Hegele's response, many researchers and health professionals believe that the thrifty genotype hypothesis accounts for why type 2 diabetes has rapidly taken on epidemic proportions in indigenous communities world-wide.

It is debated whether this hypothesis applies solely to populations whose immediate ancestors relied on hunting and gathering for subsistence, or only to populations whose immediate ancestors lived in environments that did not yield ready, steady access to food (Szathmary 1994). A recent and very critical review notes that contemporary interpretations of the hypothesis tend to attribute “thrifty genes” to marginalized “races,” whereas it was first proposed “as an explanation for an almost universal phenomenon” (McDermott 1998, 1194).

Neel originally postulated that, by keeping blood sweeter than normal, a “thrifty gene” would confer a survival advantage in times of food shortages, presumed to be frequent in the hunter-gatherer and pre-industrial agricultural societies of “our” forebears (Neel 1962). Twenty years later, he revised the hypothesis to cover type 2 diabetes only, as opposed to type 1 diabetes, and he suggested further study on manifold genes (Neel 1982). “All these speculations may be utterly demolished the moment the precise aetiologies of NIDDM [non-insulin dependent diabetes, or type 2 diabetes] become known,” he owned. “Until that time, however, devising fanciful hypotheses bases on evolutionary principles offers an intellectual sweepstake in which I invite you all to join.”

In March 1999, Dr Hegele and his team published an article indicating that the presence of a genetic mutation that affects the structure of a liver protein – hepatic nuclear factor-1 $\alpha$  G319S – predicts the onset of type 2 diabetes (see Hegele et al. 1999). This mutation was not found in other First Nations in Canada, nor within any other ethnic groups in Canada, suggesting that only Oji-Cree have developed this mutation.

In all, the researchers found that about 40% of Sandy Lake residents with type 2 diabetes have at least one copy of the mutation. The researchers found that a Sandy Lake resident with one copy of the mutation was more than twice as likely to have diabetes than was a neighbour or family member who did not inherit the mutation. Meanwhile, people with two copies of the mutation were up to 15 times more likely to have type 2 diabetes.

Dr Hegele and his team also found that the mutation accelerates the sweetening of blood. On average, people with one copy of the mutation had developed diabetes in their 30s, but those with two copies tended to have diabetes by their late 20s. The researchers identified only one adult with two copies of the mutation who did not have type 2 diabetes; this individual was 25 years old at the time. The Sandy Lake study, however, was the first to show a relationship, mediated by a gene, between diabetes *severity* and a liver protein.

The original scientific publication did not explicitly claim that these findings support the thrifty gene hypothesis, but the press coverage did. For example, the *Globe and Mail* reported:

Dr Hegele suspects the mutation works by triggering the bodies of the Oji-Cree to treat every calorie they consume as a treasure to be stored – a thrifty gene that enabled them to survive famines between successful hunts when they lived as nomadic tribes. But now ever-plentiful junk food and the sedentary reserve life may have made the gene a potential killer – endlessly storing calories that may never be used.

‘It certainly has all the earmarks of what a thrifty gene would be,’ said Dr Hegele, who added that there is evidence that the mutation has existed in the Oji-Cree for several generations.

(Abraham 1999; see also *Montreal Gazette* 1999).

Dr Hegele explained to journalists, who explained to “the public,” that the current epidemic of type 2 diabetes in Sandy Lake is a signature of colonialism. This signature is especially pronounced, Dr Hegele suggested, because the bodies of the people of Sandy Lake bear a strong imprint of oscillations between feast and famine borne by previous generations. More specifically, the mutation found to predict the onset of type 2 diabetes among people living in Sandy Lake today probably helped their predecessors survive food shortages. In this sense, the gene does not *cause* disease on its own. Instead, sweet blood and associated “complications” arise through interactions – mediated by and expressed in physiological processes – between the gene and the ambient environment.

While the gene in question does not, strictly speaking, cause diabetes, its characterization does provide a biological basis for defining Oji-Cree sub-populations. Certain Oji-Cree are now deemed similar, akin, because they possess two copies of this mutation, as opposed to one or none. The presence of one or two copies of the mutation exponentially increases the probability of developing diabetes – as well as the “complications” associated with diabetes – over the life span. Ultimately, people born with the mutation seem poised to die at younger ages and in poorer health than immediate family members, neighbours and other people around the world who also live in a “predisposing environment” yet do not have this mutation. Yet, as noted above, Dr Hegele believes that one potential tangible benefit of genetic research on sweet blood is that it may inform timely, tailored, and therefore effective interventions to prevent or curb its effects (see also Hegele et al. 2000).

### **INSIDE OUT AND OUTSIDE IN**

Current biomedical knowledge about the origins of sweet blood confirms Young’s chief observation about variation in explanations for human sickness, namely, that explanations differ in whether they attribute the origins of sickness to events *inside* or *outside* the confines of sick bodies. Nevertheless, my investigation of how biomedical researchers conceive the origins of sweet blood qualifies Young’s classification of medical systems. Biomedicine may generate the most internalizing accounts of the origins of disease ever known in human history (Young 1976, 158), but biomedical knowledge is not confined to the insides of individual human bodies. Some biomedical accounts *externalize* the origins of disease, especially through the use of statistics to create and study populations whose members are geographically and temporarily dispersed. In addition, my analysis questions the notion that anthropologists can rank accounts of the origins of sickness by the extent to which they externalize.

*Internalizing* accounts may vary in the number of body parts implicated and the degree to which these different parts are thought to interconnect. Using

the individual human body as a unit of analysis, anthropologists can rank *physiological complexity* in various medical systems.

*Externalizing* explanations, however, can only be contrasted, not ranked. Accounts of the origins of sickness that privilege processes, events and agents external to human bodies are *incommensurable* because they interpolate axes – notably axes of time and space – in attributing causality. If linear time measured out in years and a geographic grid provide the basis for comparison, these axes appear to distend and contract. Biomedical accounts that locate the origins for sickness outside a given human body are neither more nor less externalizing than accounts that invoke the will of beings other than the embodied self (see Figure 16).

Contemporary anthropologists are well aware that biomedicine co-exists with other epistemologies – as when voodoo and pharmaceutical products treat “the same” case of tuberculosis and HIV (see Farmer 1992). This chapter suggests that biomedicine itself exhibits pluralism: biomedical research and clinical praxis rely on different epistemologies to reckon the origins of sickness. In biomedical clinics, therapeutic decisions follow from diagnoses, which internalize the origins of sickness. The “clinical gaze” remains riveted on the physiology, the inner workings, of individual bodies (Foucault 1973). Nevertheless, research on populations invariably informs the clinician’s interpretation of diagnostic tests. Such research locates the origins of sickness, the roots of pathology, *outside* sick bodies and well beyond the clinic (cf. Canguilhem 1989 {1943,1966}). Biomedical research, in this respect, resembles “supernatural” causes for sickness.

The internalizing/externalizing distinction implicitly privileges an understanding of the body as a discrete material entity bounded by skin, underneath and throughout which physiological processes run their respective courses. This understanding pervades “the West,” and it certainly informs biomedicine. Yet ethnographic findings serve as a reminder that unexamined assumptions root “our” tacit knowledge about where human bodies start and finish.

**Figure 16:**  
**Origins of sickness revisited**

**Internal to the Sick Body**



Physiology (Mechanism)

Examples:

- Ayurvedic Medicine
- Biomedical Diagnosis, Treatment

**External to Sick Body**

Etiology (Cause)

Examples:

- Witchcraft, Magic, Spiritual Beings
- Biomedical Research

Not all societies have conceived the human body as tightly bound by its skin. Often, “it is mapped onto the world” (Sharp 2000, 313). For example, Aboriginal people in Australia have been profoundly affected by the Western assumption that people “own” land, rather than spiritual beings creating, transforming, sensing, and knowing people through the landscape (Povinelli 1993). The presence of Aboriginal people – “just sitting” – generates value that is simultaneously economic, social, and spiritual. They become “properties” of the sentient countryside (the Dreaming), not the other way around.

The realization that human bodies do not constitute “natural” units is crucial for anthropologists who examine biomedical knowledge, for biomedicine simultaneously reinforces and departs from “Western” wisdom about human bodies and societies. Of particular relevance here, biomedical praxis construes the human body as a uniform yet unique material entity with palpable, inviolable boundaries *for some purposes*. But biomedical researchers do not stop at the individual human body.

Large groups – populations – constitute “the” scrutinized body in externalizing biomedical accounts. Populations are imagined as a compound entity, collections whose members may span recognized geographic, temporal, and biological boundaries (pace Anderson 1991 {1983}). The agglutination of many bodies into populations unsettles, but does not entirely unseat, a truism in “the West”: that individual bodies root singular subjects. When biomedical researchers coagulate individual bodies into variegated populations, whose porous and differentiated component bodies are defined as sharing degrees of substance with one another, attention fastens upon events and processes external to individual bodies to uncover the origins of sickness.

Biomedical knowledge about what is happening inside a particular sick person’s body (diagnosis) takes on material and intelligible form *outside* of that person’s body, in situating that particular body within populations fashioned by researchers. Biomedical researchers analyze columns of numbers, diagrams, and three-dimensional figures that represent human beings or animal models.

Inscriptions and other material ways of rendering the bodies of humans and other animals fix – objectify – the inner state of a particular organism at a particular time. Once inscribed on a piece of paper, caught on a computer screen, or converted into malleable three-dimensional models, these “technological analogies” stand for the bodies from whence they came; they purport to represent accurately the internal workings of human or animal bodies. Further, such technological analogies facilitate aggregation, disaggregation, and stability over time and space (pace Latour and Woolgar 1986 {1979}; Latour 1990; Francoeur 1997; Young 1976).

To discern the origins of sickness, biomedical researchers conjure the past and the future through a statistical lens. They may privilege the probable impact of interactions with the social and physical environment over a lifetime, or they may trace the distribution of genes across populations and the transmission of genes from one generation to the next. To understand the etiology of diabetes, for example, biomedical researchers have been concerned with gene transmissions from both human and non-human ancestors that correlate with sweet blood and its “complications.” They have also drawn attention to how contemporary environmental conditions – physical and social – may unmask a genetic predisposition that remained latent, or even served an adaptive purpose, among previous generations. Contemporary genetics is neither more biological nor less social than other modes of thoughtful action (pace Rabinow 1992); but contemporary genetic researchers do construe “biology” and “society” in some distinctive, changing ways.

By genotyping sweet blood, researchers discern biological likeness among *certain* diabetics alive today, as well as among people who lived in the past. Genetic explanations for sweet blood suggest that susceptibility threads through lines of biological descent. In keeping with the tenets of evolutionary theory, these lines of descent include humankind's distant relatives, “lower” nonhuman beings.

In genetic research, the notion that all people and indeed all organisms are related, albeit to varying degrees, if the lines of descent are traced far enough back has a matter-of-fact quality (cf. Strathern 1996, 529-530). Evolutionary theory and genetic research thus unifies all human beings: we constitute “like kinds” because we have similar bodies containing similar parts. Yet a common heritage does not preclude differences, genetic research has shown, even within small populations and immediate families.

Genetic researchers take physiology as a starting point in defining the bodily quality of interest to them, but they train their attention on underlying genetic structures, or rather, on statistics and other inscriptions that represent the genetic structures found in biological samples. Genetic models burrow even deeper into the body than physiological models, into the array of genes contained within the cell nucleus and within the mitochondrion. Ultimately, genetic researchers want to understand how genotype contributes to physiological phenotypes, such as sweet blood.

Genetic models would *appear* to internalize to a greater degree than physiological models, but appearances sometimes deceive: genetic explanations, in fact, *externalize* more than they internalize. To explain the presence of certain genes and their effects in a given organism at a given time, genetic researchers inevitably invoke external events. These externalities comprise genetic inheritance from one’s parents, evolutionary changes over time, and interactions, mediated by genotype, between the external environmental and the individual body. Just when the biomedical researcher’s gaze seems directed to the very most inner reaches of the body – the preserve of genes – the focus of attention inverts: events outside the sick human body become the focus of scrutiny. In other words, *this* biomedical gaze ultimately externalizes rather than internalizes.

Conception, when the single cell from which an entire body will grow comes into being, measures out a precise amount of familial (and evolutionary) heritage. Conception takes place within an individual human body and sparks a unique life, but depends upon external bodies. More specifically, two stands of

DNA – each from a different human being, both distinct yet similar incarnations of evolution – intertwine at the moment of conception. From this moment through to death, “the environment,” together with genes, modulates the perpetual renewal of the body through such means as the production of proteins and the death of cells.

The human genome and that of mitochondria in human cells comprise many strata, some of them dating back millions of years. When experimenters gaze upon genetic stratigraphy to understand the causes of disease, their focus shifts from inscriptions representing the inner reaches of bodies racked by sickness to inscriptions representing external events, places, people, and kindred organisms. At this juncture, suddenly, vast expanses of time and space unfold. As shown in this chapter, genetic explanations for the origins of diabetes in humans implicate the mitochondrion, the major histocompatibility complex, and the insulin response system – and thus the evolution of human beings as well as nonhuman beings around the world over millions of years.

This analysis qualifies the geneticization thesis. In an oft-cited article in which she coined the term, Lippman found evidence for geneticization in mass circulation magazines and professional journals alike, particularly as regards prenatal testing for genetic abnormalities in the fetus (Lippman 1991). Geneticization extends the concept of medicalization, the process whereby social problems become framed as individual pathologies. In recent years, disillusion with biomedicine has become widespread in “the West,” partly buttressed by and partly reflected in social science scholarship on medicalization (Williams and Calnan 1996). Lippman and many others argue that, more and more, genetic models and technologies threaten to reduce the complexity of human behaviour and the composition of human bodies to, in essence, functions of genetic codes (Nelkin 1996; Petersen 1998, for example).

In contrast to the geneticization thesis, the genetic researchers cited in this thesis do not rely on genotyping to define disease (cf. Lippman 1991, 18). The definition of diabetes as a disease remains tied to physiology, to a phenotype in

which the sweetness of blood indexes misfortune. Further, these researchers regard the sweetening of blood as the result of a complex interplay between inherited genetic susceptibilities, the lapse of time, embodied action, and social circumstance. They also implicate distant environments and practices that helped mould the biology of human populations through “natural selection.” In sum, and unlike what the geneticization concept would suggest, the causes of sweet blood do not boil down to genes in modern-day biomedicine (cf. McDermott 1998).

While genetic research has not transformed the definition of diabetes as a disease, genetic models and tools currently inform how sweet blood is managed and perceived. For instance, since the incidence of type 1 diabetes varies by haplotype, with one particular haplotype conferring a 20% risk, clinicians sometimes suggest that people with type 1 diabetes and their partners undergo genetic analysis before deciding whether to have children. And, as noted previously, when people with diabetes become candidates for kidney and, increasingly, pancreas transplants, “a good match” in genetic terms between “donor” and “recipient” may avert organ rejection (Hogle 2000 for further discussion). In addition, screening for genotypes known to confer increased risk for type 2 diabetes in certain populations, such as the Oji-Cree, may soon accompany or even precede screening for diabetes (Hegele et al. 2000).

Researchers who lean on the thrifty gene hypothesis to account for the enormous increase in the prevalence of type 2 diabetes among Indigenous peoples world-wide have often glossed the ravages of colonization as genetic destiny, and even a sure sign of genetic backwardness *vis à vis* “Westerners” (McDermott 1998). My research found that at least one cohort of medical students in Canada have been taught that the current epidemic of type 2 diabetes among Indigenous peoples results from their “stone-age metabolisms” (cf. Eaton, Shostak, and Konner 1998 {1988}). As such an interpretation of the thrifty gene hypothesis suggests, the use of genetic differences to explain the distribution of sweet blood can lead to “naturalizing” social inequality.

While specifying that pathology is rooted in phenotypes, genetic understandings of human biology and of evolution have suggested the existence of a pan-human “normal” genotype, with some people seen as more “normal” than others. Yet, in itself, the identification of phenotypical or genotypical differences among human beings does not foretell the social implications of these distinctions (after Lock 1993b). The intermingling of “genetic” *and* “environmental” causes for sickness raises – without resolving – questions about culpability. Since individual actions, biological endowment, and social arrangements index one another in the visitation of sweet blood, the onset of sickness appears *partially* subject to individual and collective will.

## **6. “Politicians, You have to Hit their Radar”: Making Diabetes Count in Canada**

By 2000, diabetes constituted a target for Canadian health and science policies. In terms of an idiom that I encountered many times during fieldwork, diabetes registered “on the radar screen.” This chapter examines how diabetes became more visible within the Canada’s federal government from 1990 through 2000. The diagnostic criteria, screening recommendations, and research practices analyzed in the three previous chapters helped define sweet blood as a something worthy of greater attention and more public funds. By associating diabetes with current and, in all probability, future members of the Canadian population, biomedical knowledge buttressed calls for increased public funding to measure and redress the impact of sweet blood in Canada.

One of the key findings of this thesis is that statistical technologies contribute to governance by commodifying human bodies and their parts. This chapter highlights how politicians, their advisors, bureaucrats, researchers, and representatives of diabetes-related organizations deploy inscriptions to portray populations and their individual members as having varying worth, diverging needs, and different possible futures. Measures such as the diagnostic criteria for

diabetes and average life expectancy codify, and even generate, standards with which to compare lives, judge bodies, and justify the allocation of resources.

Increased recognition of diabetes by the Canadian government hinged upon associating sweet blood with preventable health problems. In other words, politicians, their advisors and bureaucrats recognized diabetes as a serious problem by fastening onto the hope, ramified by statistics, that judicious interventions could, over the long term, exchange populations plagued by health problems for populations approaching “normalcy” to a greater degree. The emphasis on prevention, so striking in recent Canadian policies and projects to redress diabetes, reflects the increased importance attributed to “health risks” in recent history. Since the mid-1960s, epidemiological findings have engendered a veritable “risk epidemic” (Skolbekken 1995), such that all manner of behaviour and bodily features predict certain kinds of suffering, and even certain kinds of death. Accordingly, future health status currently preoccupies individual citizens, researchers, and governments alike.

In this chapter, I examine how diabetes gained a higher profile in a climate saturated by concern about future health status: sweet blood constituted but one bodily condition linked to reduced expectations about length and overall quality of life. In this competitive situation, increased recognition for diabetes depended heavily upon binding diabetes more tightly to prospects for longer, healthier lives. To elevate awareness about diabetes and convert this awareness into public funding, diabetes organizations and researchers argued that the *magnitude* by which diabetes erodes longevity and overall “quality of life” has not received due attention, nor resources. To support claims that sweet blood is wreaking havoc, diabetes organizations and researchers also drew attention to the untold economic impact of diabetes in Canada. Yet, they argued, control over the sweetness of blood – through concerted action by governments, professionals and citizens alike – could duly align everyday realities with core commitments.

New diabetes-related policies and projects in Canada did not flow directly or simply from such “reasons,” but they needed to pass muster as “reasonable”

before becoming phenomena suited to thick, ethnographic description such as I present here. Below, I chart how diabetes became understood as a seemingly target for public funds in Canada. To begin, I discuss theoretical analyses of liberal governance, including similarities and differences between Foucault's conception of "governmentality" and "biopower." The concept of "governmentality," I suggest, encompasses and aptly delimits the phenomenon of "biopower." To appreciate how diabetes became recognized as a social problem, however, I have had to recast Foucault's understanding of how individual bodies fit within populations. Following this theoretical discussion, I produce evidence to support my claim that diabetes gained increased recognition within the Canadian government during the 1990s. Then I pick apart the "craft of politics" in contemporary Canada by tracing trends and events that helped shape the Canadian Diabetes Strategy (launched in 1999) and the Canadian Institutes for Health Research (launched in 2000).

### **CONCEIVING AND GOVERNING POPULATIONS: THEORY ABOUT PRACTICE**

This chapter suggests that, in liberal democracies, opinion poll results, "softer" indicators of public opinion, financial forecasts, and epidemiological data all serve a function similar to radar and indeed oracles for politicians and their advisors: they detect potential dangers and opportunities, partly by indicating shifts over time. High-ranking politicians and those who "have their ears" can certainly position an issue on "the radar screen," but only if the issue "has legs." Thus, lobbyists often rhetorically embed their concerns with an issue (such as health care, or economic growth) that already registers "on the radar screen." Diabetes grew "legs" within Canada's federal government during the 1990s because it embodied such concerns as health, health care, and overall "quality of life" – key concerns for "senior citizens" and "boomers," two large groups of voters – while also permitting the federal government to claim progress in redressing disparities in between Aboriginal peoples and "the general population."

In theorizing linguistic and cultural pluralism in liberal states, Charles Taylor suggests that minorities effectively compete for recognition from governments (Taylor 1992). His analysis turns upon the premise that extant “minority” and “majority” identities inform the “politics of recognition.” Pluralism begets competition, he implies.

To understand how diabetes became recognized as a public health disorder by the Canadian government, Taylor’s understanding of the politics of recognition would suggest that particular linguistic or cultural groups must first identify diabetes as a threat. This framework might appear to account for why diabetes gained recognition as an Aboriginal health issue. Extending this framework to encompass generations in a society, it could be argued that diabetes is inherently of concern to “senior citizens,” “boomers,” children with diabetes, and their parents. Yet by portraying personal and collective identities as political motors, Taylor’s framework glosses over how diabetes has become associated with certain “types” of people. More specifically, Taylor does not account for the practices that concoct populations, which feed the “politics of recognition.”

Foucault introduced an alternative “full-bodied” approach to understanding politics in liberal states, which he termed “governmentality.” This concept has inspired a rich secondary literature in sociology (see O’Malley, Weir, and Shearing 1997 for review). Relatively few anthropologists have invoked “governmentality” (but see Adams 1998; Escobar 1999; Pels 1997; Shore and Wright 1997; Thomas 1994). Another concept coined by Foucault, “biopower,” has been very influential in recent anthropological engagements with “the body” and medical systems (Lock and Kaufert 1998; Lock 1993a; Rabinow 1992). Below, I contrast how Foucault delimited these terms and the phenomena to which they refer. Then I tackle their pertinence for understanding how and why the Canadian government recognized diabetes as a public health problem and, as such, a legitimate target for public funds.

Foucault conceived “biopower” as spanning two poles (Dreyfus and Rabinow 1982, 134-135; Foucault 1976, 182-183). Efforts to control populations

(the “species body”) characterizes the “bio-politics” pole, while the desire to wield control over the individual body-as-machine informs the “anatomy-politics” pole. These poles both developed in Classical Greece through the interplay of discourse and material human bodies. They remained essentially separate until the beginning of the nineteenth century, Foucault claims, when they became linked in nineteenth-century Western Europe through a preoccupation with sexuality and reproduction. Prior to that time, Foucault suggests that the governance of populations and the governance of individual bodies ran parallel to one another, rather than entwining. But in the nineteenth century, a new form of power emerged that explicitly construed individual bodies as the base units of populations. Under the auspices of “biopower,” efforts at control oscillate between targeting populations and targeting individuals, Foucault implies, such that biopower forms a continuum (Foucault 1978 {1976}, 183)

Foucault also dates the emergence of fully-fledged “governmentality” to the nineteenth century, when governance became understood in European societies as the *convenient* arrangement of *things* through the application of economy to the creation, maintenance, and reproduction of populations. Beginning in the eighteenth century, says Foucault, “economy” came to designate a level of reality, a field of interventions, rather than a feature of a household. “The economy” became a sphere in which things circulate. Statistics were the “major technical factor” underpinning this rupture. Notably, the things in circulation came to include statistical imbrications of human bodies with such things as wealth, sickness, and territories.

Statistical innovation intensified the governance of entire states, Foucault contends, because statistics rendered the state as a thing composed of resources, including an agglomeration of human bodies (Foucault 1994 {1978}, 651). A massive increase in the availability of statistics in the nineteenth century enabled new ways of conceiving, ordering and manipulating people, places, and other entities (Foucault 1994 {1978}; see also Hacking 1982; Desrosières 2000 {1993}).

Statistics represent individual people as a particular sort of thing, a printed number. As such, statistical operations can combine and disaggregate people-as-things to form populations whose spatial and temporal composition vary; they traverse social and geographic distances; they privilege prediction over decree; they can be used to identify categories or “types” of people; and these categories can become incorporated into personal and social identities (Desrosières 2000 {1993}; Hacking 1990; Hacking 1986; Latour 1990; Rose and Miller 1992). Further, statistical manipulation of individual bodies and entire populations takes place at a distance, seemingly leaving persons unscathed.

All empires have had ways of tallying these and other contents, but it appears that the population concept first became truly indispensable to the conception and practice of governance in nineteenth-century Europe. How did this happen? Simply put, people printed column upon column of numbers on pieces of paper, and then tried to make sense of it all (Foucault 1994 {1978}; Hacking 1982). Yet European expansion and colonization prior to the nineteenth century undeniably contributed significantly to this process. “Slaves” and “natives” became self-consciously construed as resources to be managed, even dislodged (Appadurai 1996, chapter 6; Hacking 1982). Partly as a result, food became more plentiful in Europe, which led to population growth and, in turn, to new ways of managing “peasants,” land, “labour,” and machines (McKeown 1976; Mintz 1985). In these regards, through the statistical rendering of human populations, the emergence of “biopower” greatly facilitated the rise of capitalism (Foucault 1976, 185) – and trenchant critiques thereof (Marx 1954 {1887}; Engels 1973 {1892}).

In writing about biopower, Foucault does not directly address the commodification of bodies, a key concern of this thesis, other than through the rubric of labour. Yet he hints that the proliferation of desires allows biopower to flow through and propagate within human bodies. He also suggested that “life itself” has become something that people routinely imagine that they –like Faust – can barter, improve, or lose in calculated fashion (Foucault 1976, 188-191, 206).

Meanwhile, his theorizing about “governmentality” attends closely to “the economy,” if not commodification *per se*. Under “governmentality,” the management of populations and component bodies encompasses the exchange of labour and other things, Foucault explains. So constituted, “the economy” appears to unfold in a sphere distinct from other demarcated realms, including that of “politics.” The latter comprises relations among persons defined as political subjects. The governance of populations-as-things may transverse “the economy” and “politics,” however, as when persons may “legitimately” buy or sell labour, or when tax dollars pay for clinical consultations.

“Governmentality” and “biopower” suit liberalism, which construes its ideal subjects as persons who bear rights, exercise freedoms, exhibit industry, and fulfil responsibilities. These virtues are said to arise from how liberal subjects deploy their possessions, beginning with their bodies (cf. Rose 1993; Sharp 2000). Hence, modalities other than brute physical force applied to the body play integral roles in the exercise of power under liberalism. Liberal governance invites questions about how to govern to the least extent possible and at the least possible cost (Foucault 1994 {1979}, 820). In the name of economy, liberalism calls upon subjects to govern themselves, with the state apparatus cast as enforcer. Paradoxically, this commitment to “minimal governance” in the name of “the public good” and the “best interests” of its subjects underpinned the colossal intensification, geographical expansion, and manifold permutations of “Western” governance over the last 150 years or so.

Foucault coined “biopower” and “governmentality” to underscore the importance of technologies that, in conjunction with “problems” exhibited by large numbers of bodies, render populations thinkable. In that biopower and governmentality entail, respectively, the presence and economical management of populations, these concepts *only* apply to societies that are large in scale in which statistics abet governance. *If* and only *if* face-to-face communities, households and individuals become construed as component parts of populations do they exhibit “biopower.” The complex of power and knowledge to which “biopower” and

“governmentality” refer depends upon statistical technologies to detect, elaborate, and ramify differences, including linguistic and cultural identities. Hence, the exercise of “biopower” and its corollary, “governmentality,” have *very* restricted application historically and cross-culturally – notwithstanding the creative use of these concepts by anthropologists to understand the embodiment of politics in variety of settings.

The distinction between qualitative and quantitative research, often raised to a pitch in debates about methodology and discipline, belies the foundational status of the population concept in all social sciences. Even if the “qualitative” researcher does not manipulate a single numerical value, the population concept epistemologically underpins the research process. Ethnographic inquiries invoke the population concept by conceiving all societies and each person as representative of a universal yet variegated humanity (see also Desrosières 2000 {1993}, 285-287). By deploying the populations, however tacitly, ethnographers identify similarities and differences (for example, the presence or absence of something resembling “the state” in “the West”).

The ethnographic research project at hand explicitly focuses on the population concept, and more specifically, on the use of statistics to identify, characterize, and valorize human beings. In sifting through the interview transcripts, speeches and other documents amassed during my fieldwork, I have discerned that Foucault ultimately reproduces a micro-macro dualism in conceiving “governmentality,” and even more so, in conceiving “biopower” (cf. Shore and Wright 1997). Recall that, according to Foucault, “biopower” consists of a series of relationships that link individuals to form populations (Foucault 1976, 182-183 « deux pôles de développement reliés par tout un faisceau intermédiaire de relations »). He suggests that “governmentality” links, relates, and even imbricates individual human bodies with populations, and with such things as money and territory (Foucault 1994 {1978}, 643-644 « rapports, liens, intrications»). This thesis underscores the semantic difference between “links” and “imbrications.”

The governance of populations *imbricates* individual bodies because each individual body forms part of numerous populations, and vice versa (cf. Foucault 1994 {1978}, 638-639). Insofar as individual bodies and populations are “related,” they form synecdoches, wherein each part (each individual body, sometimes equated metonymically with “parts” such as organs and blood samples) represents the whole (the population). Individual bodies represent examples, more or less “typical,” of populations; meanwhile, populations comprise and congeal individual bodies. Rather than representing the population in miniature, individual instantiations form part of a variegated mass that, if graphed, might resemble a “normal” curve. Foucault, however, implies that human bodies exhibit such uniformity that “the” population forms a macrocosm linking together individual microcosms. Yet, as illustrated by biomedical research on the genetic origins of sweet blood, great attention and concern routinely attend minute differences within this mass.

#### **POLITICALLY SPEAKING: DIABETES IN FEDERAL CIRCLES, 1989-2000**

To demonstrate and help account for the increased recognition of diabetes in Canada during the 1990s, I traced references to diabetes entered in the *Hansard*, the official record of the Canadian House of Commons, which transcribes politicians’ speeches verbatim.

Following British tradition, time in the House of Commons is metered out in “parliaments” and “sessions,” which vary in start dates, end dates, and the number of days in between. A majority government may call an election at its discretion within its mandate; all governing parties in Canada since 1979 have held majorities. Federal elections punctuate the end of one parliament and the beginning of another.

Each parliamentary session begins with a Speech from the Throne, crafted by the government of the day but delivered by the Governor General of Canada, who officially represents the Queen of England. The Governor General gives this

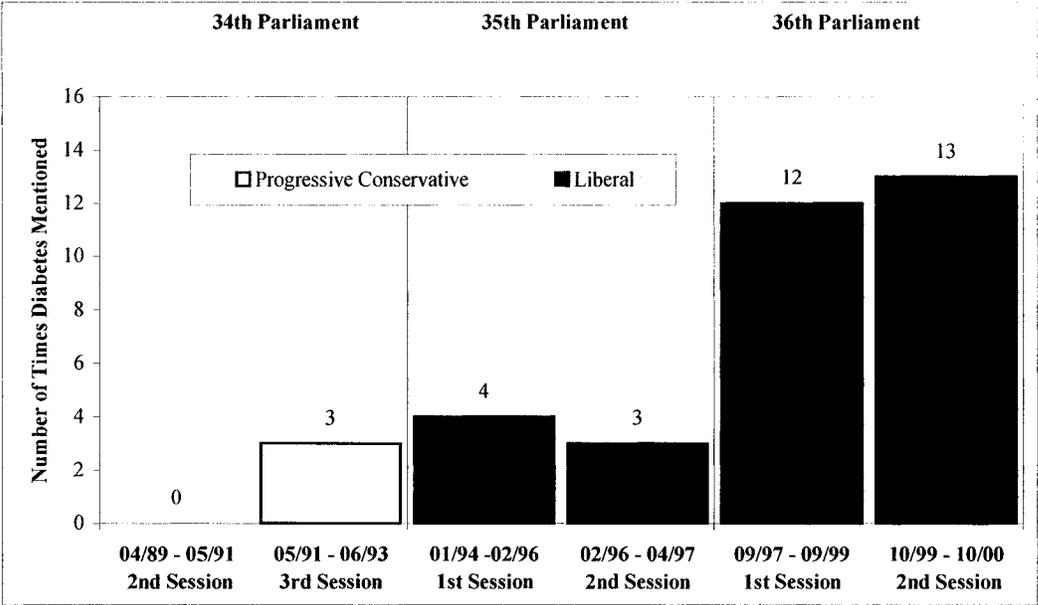
speech in a special session of the Senate that elected members of the House of Commons may attend. (In Canada, federal governments appoint senators.) In an exercise of pomp and circumstance, the Speaker of the House of Commons reads the text aloud later that day, and thus, the Speech from the Throne appears in the *Hansard*.

In a thesis that investigates some of the powers of quantification, there is a certain irony in creating a modest graph that purports to indicate changes in the political fortunes of diabetics, diabetes researchers, and diabetes-related organizations. Irony aside, Figure 17 displays the number of speeches in the Canadian House of Commons, from 1989 to 2000, that referred to diabetes. Figure 17 also records the governing party of the day for each of these speeches. Figure 18 displays the same time-series data, but by topic. Note that in the last period surveyed here, the second session of the 36<sup>th</sup> Parliament, “diabetes” became a *Hansard* index category. Previously, the index category “health” subsumed references to diabetes under a variety of sub-categories. These figures suggest that diabetes became increasingly present in political discourse in Canada throughout the 1990s, to the point that diabetes warranted its own heading in the *Hansard* index, but it never became a paramount concern. My analysis of the speeches naming of diabetes in the House of Commons revealed that their timing and the issues raised accord closely with retrospective accounts, gathered in formal interviews with insiders, of how diabetes gained a higher profile in Canada during the 1990s.

It bears underscoring that the second session of the 36th parliament, which included the more references (13) to diabetes than any other session, ended in October 2000 because the Liberals called a federal election for 26 November 2000. Had the session ended in November or December 2000, the count would likely have been higher.

November was first declared “Diabetes Awareness Month” in 1990 – a development that I discuss in greater detail in the next chapter. The choice of the month of November honours the anniversary of Dr Frederick Banting’s birth on

**Figure 17:**  
**Rhetoric about diabetes in the**  
**Canadian House of Commons**  
**by governing party, 1989-2000**



**Figure 18:**  
**Rhetoric about diabetes in the**  
**Canadian House of Commons**  
**by topic, 1989-2000**

<i>Hansard</i> Index Category	89/04 - 91/05 34th Parliament	91/05 - 93/06 34th Parliament	94/01 - 96/02 35th Parliament	96/02 - 97/04 35th Parliament	09/97 - 09/99 36th Parliament	99/10 - 00/10 36th Parliament	Total
<b>Health</b>							
Diabetes Awareness Month, Diabetes Day, Diabetes Week	3	3	1	5			12
Aboriginal peoples/communities, diabetes, type 2		1		3			4
Diabetes, Aboriginal peoples/general population, incidence			1				1
Diabetes, treatment, insulin, discovery, 75th anniversary			1				1
Diabetes, Ayden Byle Diabetes Research Foundation				2			2
Diabetes, Combatting, \$55 million, Budget 1999				2			2
<b>Diabetes</b>							
Diabetes Awareness Month, Diabetes Day					5		5
National Diabetes Control Strategy					3		3
Cure, search for, Juvenile Diabetes Foundation					3		3
Research, prevention, curing					1		1
Type 1, potential cure					1		1
<b>Total</b>	<b>0</b>	<b>3</b>	<b>4</b>	<b>3</b>	<b>12</b>	<b>13</b>	<b>35</b>

Source: *Hansard* Index to Debates in the Canadian House of Commons, 34<sup>th</sup>, 35<sup>th</sup>, 36<sup>th</sup> Parliaments

14 November. Banting is commonly recognized as the discoverer of insulin, but he had help. The research took place at the University of Toronto in 1921 and garnered a Nobel Prize for Banting and three collaborators (Bliss 1982). In about half of all the times that elected federal politicians referred to diabetes in Canada from Spring 1989 to Fall 2000, they referred to Diabetes Awareness Month (14 of 29 speeches). Other speeches containing references to diabetes also took place during the month of November. For example, the federal government launched a Canada-wide diabetes strategy in November 1999, which occasioned an official announcement to that effect in Parliament. In total, including references to Diabetes Awareness Month, 23 out of the 35 references to diabetes in the Canadian House of Commons from 1989 through 2000 took place in November.

### *Diabetes as a Worthy Cause*

Throughout the 1990s, federal politicians portrayed diabetes as a worthy cause, but over the course of the decade, they increasingly portrayed diabetes as an urgent matter. In acknowledging Diabetes Awareness Month, members of Parliament frequently highlighted the efforts of diabetes organizations to improve the lives of people with diabetes through the provision of services, the funding of biomedical research, and fundraising to support such ventures. For example, on 22 November 1991, Edna Anderson, a backbencher with the Conservative government of the day, rose in the House of Commons and said:

Madame Speaker, November has been declared as Diabetes Awareness Month by the Canadian Diabetic (sic.) Association. Over one million Canadians have diabetes, which is a major cause of significant health problems and can lead to premature death. Diabetes treatment costs Canada's health care system \$2.5-billion annually. While the onset of diabetes can at times be dramatic, very frequently its presence is subtle.

The federal government plays an important role through the Department of National Health and Welfare which provides a sustaining grant to the Canadian Diabetes Association, supports

the operation of the Canadian Diabetes Advisory Board, funds special initiatives in regard to diabetes among Canada's indigenous people and supports other diabetes research. It is my pleasure to salute the efforts of the volunteers and staff of the Canadian Diabetes Association during Diabetes Awareness Month. (Anderson 1991)

A few weeks before, Beth Phinney, representing the Liberal Official Opposition, had asserted, "Although more people suffer from diabetes than any of the other non-curable diseases, the amount of money given by the federal government for research into the disease is falling behind." (Phinney 1991)

The 35th parliament began in January 1994, after the Liberals reduced the former Conservative majority to a handful of seats. Under the Liberals, diabetes received mention for the first time on 18 November 1994, when a Liberal backbencher, Janko Peric, said,

Mr Speaker, November has been proclaimed Diabetes Awareness Month by the Canadian Diabetes Association. Over one million Canadians have diabetes, with more than 13% between 65 and 74 years of age. Diabetes is a major cause of premature death, blindness, kidney disease, heart disease, stroke, limb amputation and other significant health problems. It costs Canada an estimated \$9-billion annually. The Canadian Diabetes Association is a supporter of diabetes research in Canada and provides a range of services for and advocacy on behalf of persons with diabetes and their families. I am proud to say that the federal government also plays an important role by supporting diabetes research and among other ventures a special initiative with regard to diabetes among Canada's native peoples. Please join with me in wishing the Canadian Diabetes Association and its many volunteers a very successful Diabetes Awareness Month. (Peric 1994)

Comparing these speeches highlights some key themes that have contributed to the visibility of people with diabetes as a constituency in Canada: the number of people affected, the associated monetary costs, and the possibility of serving partisan interests by arguing that appropriate policy measures have been put in place or, alternatively, that they are lacking.

The politicians cited above argued with words, to be sure, but these words derive from a series of inscriptions that link numbers synecdochally with diabetic bodies past, present, and future. In effect, when politicians recite these figures, their words carry diabetic bodies into Parliament and into politics with a capital “P.” Further, through a bodily presence in the House of Commons, members represent a bounded territory (a “riding”). Given its prevalence, politicians know that their respective ridings contain people with diabetes.

Peric and Anderson both estimate that the number of people with diabetes in Canada exceeds one million. “Estimates of the prevalence of self-reported, diagnosed diabetes in the Canadian population vary widely” and untold numbers who meet the diagnostic criteria for diabetes have never undergone testing (Canada. Health 1999c, 9). Therefore, extrapolations from American data underpin estimates of how many people in Canada had diabetes in 1996/1997, the most recent data available at the time of writing: “1.2 to 1.4 million (4.9 to 5.8 % of the population aged 12 and over), including undiagnosed cases” (Canada. Health 1999c, 7). Note that Peric underlines that the prevalence of diabetes increases with age. Given the increasing proportion of people over the age of 65 in the Canadian population, the association between diabetes and age arguably has relevance for policy, but Peric did not forecast the future in his speech.

While Anderson stated that diabetes accounts for \$2.5-billion per year in health care costs, Peric contends that diabetes “costs Canada \$9-billion annually.” The \$9 -billion figure includes costs associated with the “complications” of diabetes, such as heart disease, as well as the estimated “lost productivity” attributable to diabetes. Like the estimated number of undiagnosed cases of diabetes in Canada, dividing the counterpart American figure (see Ray, Wills, and

Thamer 1993) by ten yields the estimated economic impact of diabetes in Canada. In the absence of “home-grown” data, such calculations lean on one robust fact – Canada’s population is approximately one-tenth of the population of the United States – and two assumptions: the prevalence of diabetes in Canada is thought to be roughly the same as in the United States, and the ratio of diagnosed to undiagnosed cases in Canada and the United States is also presumed similar (see Canada. Health 1999c, 30). This estimate also brackets exchange rates. At the time of writing, one American dollar converts roughly into sixty-five Canadian cents.

Both Peric and Anderson underlined that their respective governments assist people with diabetes by funding research. Indeed, Peric and Anderson each claimed credit for an initiative to fund research on diabetes among Aboriginal peoples, created in light of evidence suggesting that the problem of sweet blood was rapidly setting in among Aboriginal peoples in Canada (Health Canada 1996; Young 1993).

Besides research, Anderson mentions that public funds support the work of the Canadian Diabetes Association and the Canadian Diabetes Advisory Board, comprised of Health Canada, the Canadian Diabetes Association, the Quebec Diabetes Association and the Juvenile Diabetes Foundation (Canadian Diabetes Advisory Board 1994). In 1995, the Diabetes Council of Canada replaced the Canadian Diabetes Advisory Board (see Figure 19). It includes all the groups that belonged to the Canadian Diabetes Advisory Board, plus representation from Aboriginal groups, charities dedicated to diseases that “complicate” diabetes, pharmacists, and the main federally-funded health research funding body, the Medical Research Council (MRC), recently superseded by the Canadian Institutes for Health Research (CIHR).

References to the discovery of insulin and the ongoing quest to cure diabetes threaded through speeches marking Diabetes Awareness Month in the 1990s. In addition, a member commemorated the 75<sup>th</sup> anniversary of the discovery of insulin on 1 May 1996 (Assadourin 1996). As a twenty-four-year-old

## Figure 19:

### Diabetes Council of Canada

# THE DIABETES COUNCIL OF CANADA (DCC)

## HISTORY

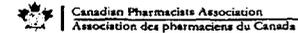
In March 1995, the Diabetes Council of Canada (DCC) was formed to unify efforts in approaching the problem of Diabetes Mellitus. The DCC succeeds an earlier organization, the Canadian Diabetes Advisory Board (CDAB). The DCC member organizations are listed below and reflect the comprehensive approach being taken to address the problems associated with diabetes.

## MANDATE

To promote the health of Canadians by influencing and coordinating strategies that address diabetes mellitus as a serious, costly, and growing public health issue and concern.

## RESPONSIBILITIES OF THE COUNCIL

- To enhance research and establish partnerships in the fight against diabetes and to increase the awareness of diabetes as a serious public health issue.
- To provide a forum to share diabetes information.
- To determine through health promotion and disease prevention research, the cost of the "burden of the disease", including its socio-economic costs and consequences.
- Upon request, to advise government about the status of diabetes in Canada.



Members: Assembly of First Nations, Quebec Diabetes Association, Canadian Diabetes Association, Canadian National Institute for the Blind, Canadian Pharmacists Association, Health Canada, Heart and Stroke Foundation, Juvenile Diabetes Foundation, Kidney Foundation of Canada, Medical Research Council of Canada, National Aboriginal Diabetes Association

with type 1 diabetes, Aden Byle, ran across Canada in 1998 to raise money for research for a cure, his efforts garnered mention twice in the House of Commons. Also, in June 1999, a member drew attention to a joint venture between the MRC and the Juvenile Diabetes Foundation (JDF) because a research group in his riding received funding under its auspices. In 2000, this same member congratulated these researchers for finding a “potential cure” for type 1 diabetes.

In November 1999, six different members drew attention to the quest to cure diabetes. While two of these members commended the Canadian Diabetes Association, this rhetorical surge may reflect the lobbying efforts of the Juvenile Diabetes Foundation. A 50-strong platoon comprised of JDF volunteers met with over 100 members of parliament, including the Minister of Health, in November 1999 to press the government into making research into a cure for diabetes a national priority (Juvenile Diabetes Foundation Canada 1999).

### ***Diabetes among Aboriginal People: A Political Problem in the Making***

The *Hansard* record suggests that an association between diabetes and Aboriginal people became established within the federal government between 1994 and 1997, which lent urgency to the problem of sweet blood.

In 1994, a Liberal backbencher told the House that epidemiological research in Northern Ontario found a fourfold increase in heart attacks and kidney disease compared with average Canadians (see Fox, Harris, and Whalen-Brough 1994). “These medical crises have a preventable cause, that is type 2 diabetes,” he said (Dromisky 1994).

In 1996, the magnitude of the diabetes problem among Aboriginal people in Northern Ontario again registered in the House of Commons when a backbencher (and future Minister of Indian and Northern Affairs) cited a study reporting a 45% increase in diagnosed cases of type 2 diabetes over five years. “Current efforts are proving inefficient to deal with the problem and the potential human and health care costs are staggering,” he observed (Nault 1996). The study to which he referred took place in Sandy Lake, Ontario. As discussed previously,

researchers found that residents of Sandy Lake had the third highest prevalence of type 2 diabetes ever seen.

In September 1997, in the Speech from the Throne that opened the 36<sup>th</sup> Parliament, the Liberal government promised to redress “the rapid increase in tuberculosis and diabetes in Aboriginal communities” (Speaker of the House 1997). In this speech, the Liberals also signalled that they would “enhance research and the dissemination of health information focussed on the needs of Aboriginal people through a new Aboriginal Health Institute,” as recommended by the Royal Commission on Aboriginal Peoples (Canada. Royal Commission on Aboriginal Peoples 1995 – get page number).

### *Mincing Words, Dollars, and Sense on Budget Day*

In 1999, the Canadian government proclaimed that the problem of sweet blood warranted special attention and its own budget line. On 18 February 1999, in tabling his budget in the House of Commons, Canada’s Minister of Finance acknowledged that “diabetes is a chronic health condition facing a great many Canadians, in particular Aboriginal peoples among whom it is three times more prevalent.” He then said, “This budget devotes important resources to addressing this serious situation.” (Martin 1999). In companion documents and speeches, the Liberals promised to create a Canada-wide diabetes strategy as part of its plans “to strengthen health care in Canada, improve the health of Canadians and enhance health research.”

As a “good news” item, diabetes received emphasis in Health Canada communiqués about the 1999 budget. An internal briefing document on diabetes and Aboriginal health was prepared to help the Prime Minister and his Cabinet, especially the Minister of Finance and the Minister of Health, field questions. A printed diabetes fact sheet entered broad circulation, and Health Canada posted an electronic copy on its web site (Canada. Health 1999b). This fact sheet specified that the Liberal government would allocate \$55-million to prevent and control diabetes over the following three years. The strategy would target diabetes across

“the entire Canadian population” and among Aboriginal peoples, according to the fact sheet. The fact sheet also reported that the government would establish a distinct Aboriginal Diabetes Initiative, “in line with the commitment made by the Government in its 1997 Speech from the Throne.” The fact sheet did not indicate how much money each component would receive.

Evidence that type 2 diabetes is three times more prevalent among Aboriginal people than among members of “the general population” in Canada, evidence to which the Minister of Finance referred in his February 1999 budget speech, came from Statistics Canada data collected in 1991 (Bobet 1997). More recent data, collected in 1997, suggest that the epidemic of type 2 diabetes in First Nations remains on the upswing. Taking age into account, diabetes is three to five times more prevalent among First Nations people living on reserves than the Canadian average (Young et al. 1999; Young et al. 2000).

Besides promising health policies and concomitant funds to redress diabetes, the February 1999 budget speech also announced science policies relevant to diabetes research. In particular, the Finance Minister Paul Martin, on behalf of the Liberal government, promised to replace the Medical Research Council of Canada (MRC) with the Canadian Institutes for Health Research (CIHR). In 2001-2002, the CIHR’s budget would reach \$475-million, the Liberals promised, or approximately double the 1997-1998 MRC budget (cut back sharply from 1994 levels in Finance Minister Martin’s 1995 budget, which emphasized deficit reduction).

The budget speech did not earmark funds for diabetes, nor any other particular health problem, in the new CIHR. Neither did the government specify at this time whether the CIHR would encompass an Aboriginal Health Institute, as promised in the 1997 Speech from the Throne.

Thus, the 1999 budget breathed life into the CIHR and into a Canada-wide diabetes strategy, but they remained inchoate. Later in this chapter, I will describe how they “rolled out,” but first, I will discuss how new policies generally take shape within liberal, democratic governments.

## **“ON THE RADAR SCREEN,” OR, THE CRAFT OF POLITICS**

During the course of fieldwork for this thesis, I noted that radar imagery recurred when discussion turned to the question of how issues become visible within Canadian governments. Radar, a visualization technology, stands for “**r**adio **d**etection **a**nd **r**anging.” It emits electromagnetic waves to sense the direction, range or presence of aircraft, ships, and other – usually moving – objects, and then graphs their locations as dots on a screen. Through comparisons enabled by intermittent screen changes, the user can picture where objects lie and how fast they are moving within a specified horizontal, vertical and temporal range.

During the Second World War, radar was used to identify such enemy targets as submarines and bomber planes. This technology became crucial to successful retaliations and to helped safeguard troops and civilians. After the Second World War, radar acquired many “peace-time” applications, including the control of air traffic and the detection of motorists travelling over the speed limit.

During my research, I noted that the profile of public policy issues was often expressed using radar imagery, implying that various policy issues constitute moving targets that may embody both opportunity and danger. The use of radar imagery also implies that a central location grounds perceptions of the significance of “policy issues.”

For the purposes of federal health and science policy, Canada’s national capital, Ottawa, occupies a central position. From their respective perches in Ottawa, the Prime Minister, his Cabinet, and their advisors scan the “political landscape” for “issues.” So do backbenchers, asking, “How will this play in Thunder Bay?” or in Come-by-Chance, or in Moose Jaw, or in Abitibi, or wherever the politician’s constituency lies. The Prime Minister, Cabinet Ministers and their advisors do not disregard the voters who inhabit such places, but they evince particular concern for the aggregate effects across the land, come the next federal election. Thus, radar imagery suggests that phenomena only become targets for policy development when, from the vantage point of high-ranking

politicians and their entourage, they appear to present enticing opportunities or they portend danger.

### *On and Off the Radar Screen*

I first made note of the radar imagery in an interview with a bureaucrat charged with the diabetes dossier in one of Canada's provinces. The "FPT" [federal-provincial-territorial government] meetings on diabetes are "highly controlled," my informant said to convey that I could not possibly attend as the proverbial fly on the wall. A description of the very first such meeting ensued to substantiate this observation.

It took place in Ottawa, the nation's capital, in September 1999, approximately seven months after the Liberals promised to tackle diabetes in the February 1999 budget. Health Canada diabetes staff sat up front, flanked by a semicircle of provincial and territorial representatives, including my informant. Additional Health Canada officials looked on from the sidelines. The representatives of the provincial and territorial governments were miffed at "the feds," my informant recalled. Over the summer, Health Canada had circulated a discussion paper outlining possible "options" for a diabetes strategy among non-governmental organizations, but Health Canada had not sent copies to provincial and territorial governments. "Diabetes is on the radar screen now," this bureaucrat declared.

Radar imagery recurred in an interview with a physician-researcher who plays an active role on the national scene. Among other things, he has played a role in the development of the National Diabetes Surveillance System (NDSS), one of three components comprising the Canadian Diabetes Strategy. Mid-way through this interview, I asked, "What do you think the value of NDSS will be?" He replied:

I think for the first time we will have national numbers. We will have both diagnosis numbers and ability to track individuals through the system and determine costs. Direct costs... And data is power. Once you have data, then you can lobby for funding,

programs, support. You can measure interventions. You can track the success of your programs. And you can develop policies based on that.

Surveillance is particularly important for raising the profile of diabetes within governments, this physician said, because diabetes does not have the emotional salience of diseases such as cancer: “It’s the big C.”

I inquired whether dramatic elements of kidney disease (transplants, dialysis, “big-time costs,” all tallied reliably in organ registries) have elevated the profile of diabetes within governments. He concurred, adding that “the *unbelievable* escalation” projected for the next few decades in renal failure due to diabetes “is one of the things that’s driving governments.” I then asked, “Bureaucrats or politicians?” He agreed that this distinction is relevant, replying, “Bureaucrats. Politicians, you have to hit their radar.”

After I observed that “a little tiny radar blip” had materialized for diabetes, my informant qualified this observation: “Federal, not provincial. It’s not hit the radar screen here. Not in Ontario.” I replied, “But you’ve had a strategy for, what? Eight years?” He pointed out that the diabetes dossier within Ontario Health is a half-time assignment for one bureaucrat. Then he shifted to an evaluation of how diabetes ranks in the various provinces. On the basis of this impromptu policy analysis, I asked, “Do you think Manitoba’s the leader?” He agreed: “Because of some of the data collection they’ve been doing. The numbers tell the story and force the issue. It’s the same as...in Sandy Lake.”

As shown above, epidemiological research in the Sandy Lake reserve and other Aboriginal communities helped move diabetes among Aboriginal people “on the radar screen” in Ottawa. The measurement and the projection of diabetes-related health care expenditures and needs do not, however, guarantee that politicians will notice diabetes. For politicians to champion an issue such as the impact of diabetes across Canada, it must be framed in terms that resonate with broader political agendas and mandates. Under the Canadian constitution, provincial governments deliver health care, not the federal government. First Nations constitute an exception. Since the Canadian constitution charges the

federal government with responsibility for Registered Indians across Canada, including the delivery and funding of health care, the impact of diabetes on this population clearly falls within the mandate of the federal government. Only by attaching strings to funds given to the provinces may the federal government affect the delivery of health care across Canada. Thus, the federal government cannot determine the allocation of health care budgets within the provinces. Health care expenditures may therefore constitute a more sensitive issue for provincial politicians than for federal politicians.

### *Values and the “Radar Screen”*

A conference on “Values and Health Policy” that I attended during the course of my fieldwork underlined that the “radar screen” imagery is not exclusive to diabetes. In fact, I came to realize that diabetes owes whatever position it has on federal and provincial “radar” to alignment with established political concerns.

McMaster University’s Centre for Health Economics and Policy Analysis hosted this conference in downtown Hamilton, Ontario in May 2000. About 120 researchers, bureaucrats, and representatives of non-governmental organizations from Canada, the United States, and Britain attended.

“It’s obvious that values discussion is on the policy radar screen,” said Ian Shugart, Assistant Deputy Minister in Health Canada’s Policy and Consultation Branch. (In Canada, deputy ministers and assistant deputy ministers link bureaucracies with elected politicians, their “political masters.”) He made this statement during his remarks as the discussant for a panel entitled, “Using Values: Tales from the Trenches.” Discussing how values fit within political process entails “a certain discomfort,” but they “are part of our universe,” Mr Shugart said. Therefore, policy-making has to take values into account. Mr Shugart observed that one reason why governments must take values seriously is that members of the public often regard “elite” or “expert” opinions as but “one set of views” that imply or conceal values. He then illustrated these statements with two

examples drawn from previous experience in the Health Protection Branch of Health Canada.

Shugart explained that “complementary medicine,” which is growing in popularity across Canada, will not be governed by the same regulations as pharmaceutical products, but through a distinct framework with a “different threshold” – that is, statistical value – for evidence of effectiveness. He also noted that social preferences and distinctions clearly drove the 1996 raw milk cheese controversy. In considering the safety of raw milk cheeses, scientific evidence alone did not determine the policy direction adopted by the federal Liberals. Raw milk cheeses are popular in Quebec, but much less so in other parts of Canada, and this mercantile fact played into policy decisions. Many Quebec voters, pundits, farmers, merchants and politicians protested vigorously when Health Canada announced its plans to withdraw raw milk cheeses from the market (Fréchette 1996). Nationalist rhetoric emphasized the “culture” of raw milk cheese, as compared to pasteurized cheese, as a feature of Quebec’s “distinct society.” As the controversy swirled, Health Canada retreated (Assad 1996; Dingwall 1996). Eventually, with the co-operation of provincial governments and the dairy industry, Health Canada embarked upon laboratory study to gauge safety concerns (Canada. Health. Federal Science for Sustainable Development 2000).

Another speaker at the “Values and Health Policy” conference deployed radar imagery in discussing the importance of health care for Canadians. Alfred MacLeod of Ekos Research Associates summarized what opinion pollsters find out about “when we go into the field and talk to Canadians.” Before joining Ekos, MacLeod served as a senior advisor to the Prime Minister and to the Minister of Human Resources Development Canada. Mr MacLeod’s presentation directly pertains to this project because the symbolic salience of health and health care, codified in opinion polls, helps explain the creation of the Canadian Diabetes Strategy and the Canadian Institutes for Health Research.

Canadians hold doctors and nurses in esteem, Mr MacLeod reported, but not politicians and, increasingly, not journalists due to a perception of bias.

Canadians trust and admire non-governmental organizations, he added. Then he produced a series of graphs suggesting that Canadians regard publicly-funded health care as contributing to a healthy population and high overall quality of life. Further, he argued, Canadians regard publicly-funded health care as a crucial symbol of national identity and unity, particularly *vis à vis* the United States; that is why debates about health care in this country are so incendiary.

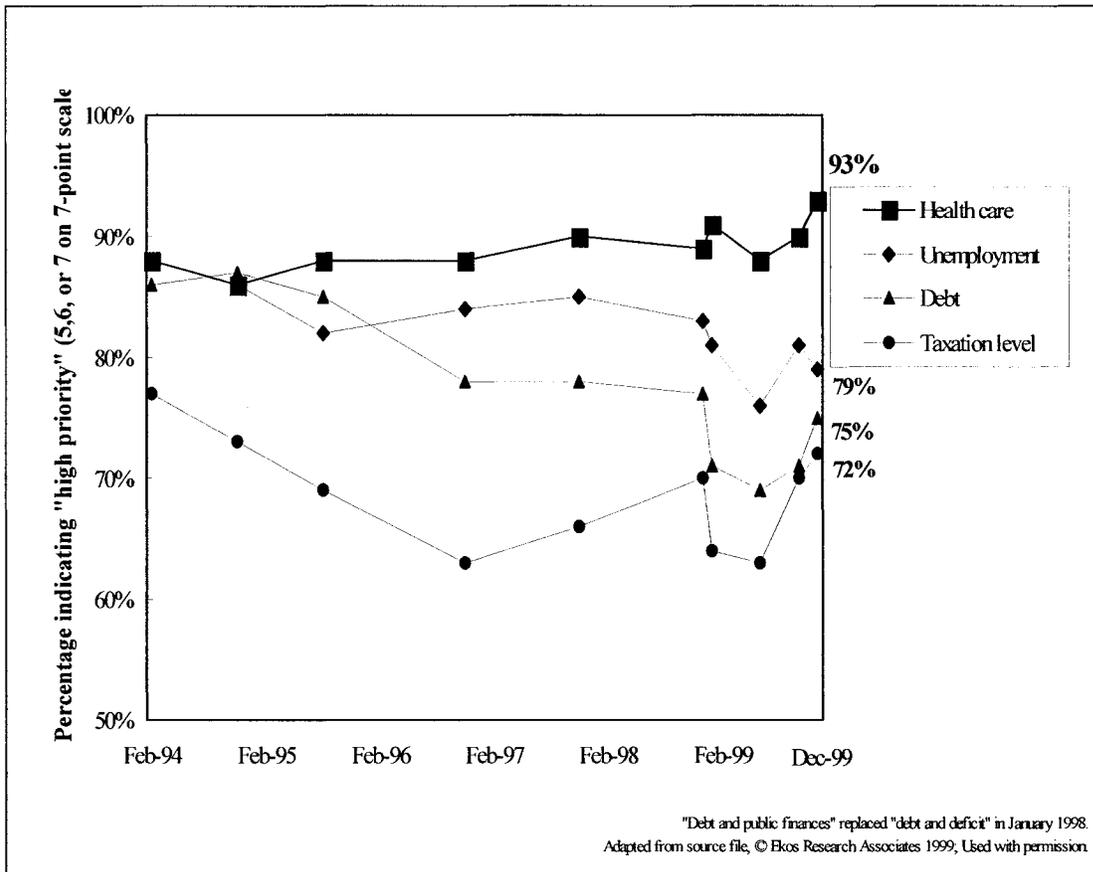
Opinion polls since 1994 have consistently found that some 90% of Canadians think the federal government should regard health care as a high priority area (see Figure 20). After pointing this out, Mr MacLeod declared, “Health care is still on the radar screen and nothing seems to budge it.” He also showed poll results indicating that most Canadians believe that the quality of the health care system declined during the 1990s, and, increasingly, they blame the federal government rather than their respective provincial governments for this perceived slide. More Canadians currently regard health care as a top priority for their federal government than any other political issue, he told the crowd, brandishing a bar graph (see Figure 21).

Note, by comparison, how low Aboriginal issues rank. No wonder a *Toronto Star* editorial declared, “[N]atives are still not on Ottawa’s political radar screen” in April 2000. The editorial in question accompanied a series of features on the living conditions of Aboriginal people across Canada. More specifically, this editorial ran on the same day that a front-page story portrayed the impact of sweet blood on the residents of Sandy Lake, Ontario as the vanguard of a made-in-Canada disaster. The article also presented the Aboriginal-focused component of the Canadian Diabetes Strategy as an inadequate response by the federal government, given the scale of the problem.

### ***Guided By Divine Providence...or Public Opinion?***

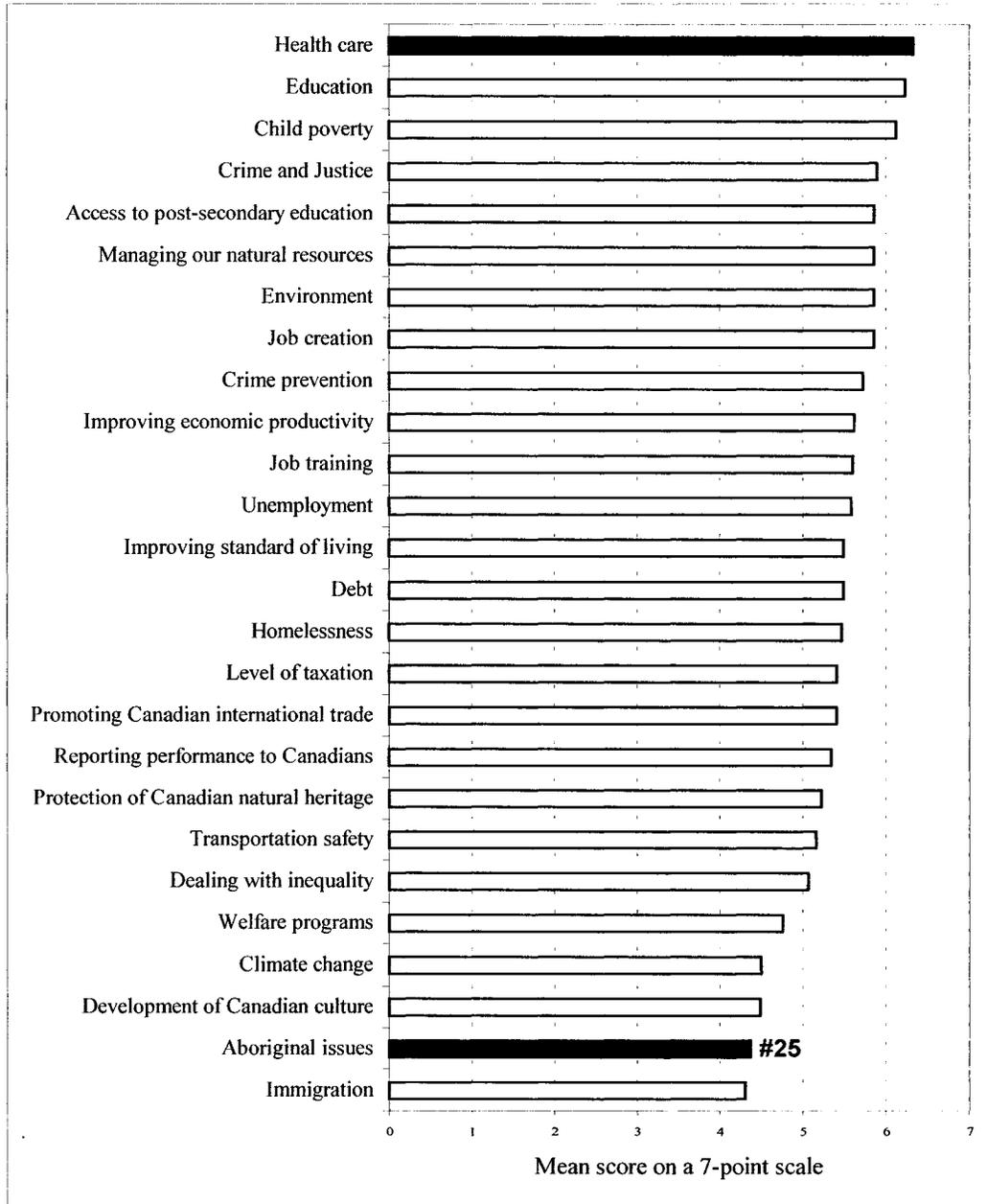
As illustrated by remarks cited above by a senior bureaucrat (Shugart) and by an advisor-turned-pollster (MacLeod), Canadian politicians divine their future and that of the populace with readings of public opinion, and they tailor their

**Figure 20:**  
**Public opinion about high priorities**  
**for the Canadian government, 1994-1999**



Exact wording of the question: "Canada is facing a series of difficult challenges. Thinking not just of today but *over the next five years*, what priority should the Government of Canada place on each of the following areas?" (emphasis in original).

**Figure 21:**  
**Public opinion about priorities**  
**for the Canadian government, December 1999**



*n*=3056

Each option asked of half sample.  
 Adapted from source file, © Ekos Research Associates.

promises accordingly. Poll results and other indicators of “public opinion” – opinion pieces published by major newspapers, letters, face-to-face meetings, briefings, and open-line radio shows – serve as “radar,” detecting issues and measuring their movement over time.

Compare the charting of “public opinion” among politicians, their personal advisors, and senior bureaucrats with Evans-Pritchard’s venerable description of the Azande’s dependence on oracles:

It is difficult to formulate the problem in our language, but it would appear from their behavior that the present and future overlap as it were.... Hence a man’s future health and happiness depend on future conditions that are already in existence and can be exposed by the oracles and altered. The future depends on the disposition of mystical forces that can be tackled here and now.

(Evans-Pritchard 1976 {1937})

Marshalling Evans-Pritchard’s famous analysis of Zande oracles to understand better the policy-making process in contemporary Canada and other liberal democracies, I contend that, for politicians and their trusted advisors, “public opinion” represents a mystical force that can and must be tackled here and now. Politicians and their trusted advisors seek to interpret and to shape “public opinion” in liberal democracies because their futures depend upon it. Statistical indicators imbricate present with the future circumstances, spelling fortune or misfortune for politicians and their advisors (after Foucault 1994 {1978}).

As I drafted this chapter, I recalled that the Speech from the Throne that opens each parliamentary session always ends with the incantation, “May Divine Providence guide you in your deliberations.” This ethnographer cannot ascertain whether Divine Providence currently informs governance in Canada and other liberal democracies, but she found that “public opinion” surely does. Pollsters’ computer screens, which interface with “public opinion,” serve as so many crystal balls. Once weighed, measured, and digested by politicians and their immediate advisors in the form of PowerPoint® presentations replete with graphs and bullet points, “public opinion” provides a touchstone for changing tacks or for staying

the course within contemporary liberal democracies. In the end, “public opinion” in each riding seals the fate of government backbenchers, ministers and opposition members alike – as well as their advisors.

The reverence for “public opinion” among politicians and their advisors in contemporary Canada stems from the collapse of “social” phenomena into the “natural” world, under the banners of social science and rational governance (Foucault 1994 {1978}). “Social” phenomena became severed from the supernatural, including Divine Providence. Religious belief itself became understood as a social fact (Durkheim 1988 {1896}; Durkheim 1988 {1912}).

Through a revolution in counting that transpired during the 1800s, a “statistical style of reasoning” emerged that renders chance as natural, and therefore ripe for taming and manipulating in the Western philosophical tradition (Hacking 1992a). The veritable “avalanche of printed numbers” that befell Europe between 1820 and 1840 fundamentally changed the nature of governance because statistical analysis of these numbers identified – nay created – hitherto unknown “types” of human beings (Hacking 1982; Hacking 1986). So represented, various “types” of people appear as things amenable to management, alongside trade balances, agricultural production, and much else. Moreover, statistics endowed “types” of people and other governable things with likely futures, and these predictions became pivotal to liberal governance.

As bureaucrats and scientists contended with the rows upon rows of figures that materialized, quite suddenly, in offices, clinics and other venues, they invented new ways of measuring and predicting all manner of things human. Through the calculation of averages, the beginning and end points of human lives became more predictable (Daston 1988). Soon sickness, debt and much else succumbed to this new way of reckoning (Hacking 1990).

Generating and grappling with reams of printed numbers led to the development of many new ways of conceiving and governing populations, including the measurement of “public opinion” as the key to the ultimate opinion poll under liberalism: democratic elections. In opinion polls, “types” of people

gathered together in a “representative sample” stand for the whole society (Desrosières 2000 {1993}, 284-287). Many social research textbooks currently in use present a heroic history of the practice of predicting election results through opinion polling (Rubin and Babbie 1993, 219-220, for example). In 1920, the first survey ever designed to predict the outcome of a democratic election took place in the United States. Owing to the “uncanny accuracy” of these polls, they grew in popularity in the United States and elsewhere.

From 1920 to 2000, the technologies as well as the methodologies used to conduct opinion polls changed significantly. During the early days of opinion polling, surveys were conducted by mail or face-to-face, usually in the respondent’s home. As telephones became standard household equipment in North America, the telephone interview became predominant because it allowed, with the same outlay in salaries, many more respondents to be surveyed over a shorter period of time: “It’s quicker and easier to let our fingers make the trips.” (Rubin and Babbie 1993, 348)

Especially since 1985, computer technology has substantially altered polling procedures. First came the punch-card revolution, which sped up the survey process considerably by dispensing with pencil-and-paper calculations. By the mid-1990s, the computer became wed to the telephone in survey research (Rubin and Babbie 1993, 350). Answers could be keyed directly into a computer instead of being recorded on a paper copy of the questionnaire, the order of the questions could undergo randomization with ease, and it became a simple matter to pose certain questions only to a select sub-sample. Overall, these technological innovations made it possible to deliver poll results much more quickly.

Together with a morass of other measures, opinion polls currently surfeit speculation about politicians’ every quality and every hiccup in “the economy.” Thus, not one but several opinion polls took place during the 2000 Canadian and American federal election campaigns, and media commentary often pivoted on their various findings. High approval ratings for the federal Liberals, reported in

opinion polls by Ekos and other firms, even informed the timing of the 2000 Canadian election.

Many ethnographers heap scorn on opinion polls as meaningless at best and misleading at worst, regarding their random samples, structured questionnaires, and confidence intervals as mere rhetoric, even so much hocus-pocus. Certainly, contemporary social theory provides the means to view explanations that invoke science for legitimacy as historically-contingent; such studies portray the quest for “universal truths” and “objectivity” as nothing more mysterious than cultural values, albeit ones with particular effects (see Daston 1988; Porter 1992). Specifically, they “harden” select realities into printed numbers, and in the process, the values that they embody may seem to disappear. A carapace of neutral objectivity seemingly shields “subjective” values. The desire to eliminate bias and human error from governance actually spurred the revolution in quantification sketched above. As Pierre Simon Laplace put it in 1814, the new science of probability aimed for “good sense reduced to a calculus” (cited in Daston 1988, 49-50)

Whether they employ qualitative or quantitative methods, very few social scientists based in academe substantially influence policy decisions in Canada. Hands are wrung. But it seems “hard” scientists do not feel that their research carries its due clout either. Indeed, the Canadian Institutes of Health Research (launched in 2000) and the Canadian Health Services Research Foundation (launched in 1997) owe their very existence to these lamentations. These concerns finally “hit the radar screen” because, as hinted above and discussed in greater detail later, they became associated with Canadians’ concern for a high quality of life. More specifically, health research became viewed as a means to “evidence-based” decisions and growth of a “knowledge-based economy.”

While academic researchers often complain about their lack of influence in the policy process, pollsters such as Mr MacLeod and senior bureaucrats such as Mr Shugart routinely affect political decisions by interpreting numbers and words that stand for “public opinion.” Politicians use their eyes and ears to detect

danger and identify opportunities, and they extend their range of vision and hearing by assembling advisors and commissioning intelligence. Through many and various ways of knowing, “political futures” articulate with whether constituents blame politicians for sickness or unhappiness. When people suffer, they may finger such things as “the market,” and they may hold politicians responsible for its relative “health.”

In summary, the craft of politics in a country such as Canada currently entails “muddling through” and “dodging bullets.” Accordingly, eyes remain firmly fastened on “the radar screen,” on public opinion. Politicians routinely ape the wisdom upon which they rely, gauge responses, and then refine their gestures. This recursive operation binds together collectives endowed with consciousness and a future: “the majority” and “the economy,” for example (after Durkheim 1988 {1912}; Foucault 1994 {1978}; Taussig 1993). Suffused with – yet constrained by – information, including budgets and balance sheets, governmental bodies cannot accede to every call on resources at their disposal. Triage is routine; administrative decisions and nomenclature form a spiral that allocates resources (Desrosières 2000 {1993}, 302-305).

The next two sections illustrate how diabetes has recently fared under triage within Canada’s federal government. First, I unravel the tangle of words and deeds that produced the Canadian Diabetes Strategy, and then I turn to the profile accorded diabetes within the new Canadian Institutes of Health Research. As discussed earlier in this chapter, the Liberal government promised both of these initiatives in the February 1999 budget. These two cases illustrate how caprice and evidence interlace in “rolling out” programs in a liberal democracy such as Canada.

### **ACCOUNTING FOR DIABETES IN HEALTH POLICY**

Below, I review the reasons given to justify the launch of the Canadian Diabetes Strategy, and I show how these reflect the epidemiology of diabetes as well as demographic trends and mandates. Given the stress on preventing and

controlling type 2 diabetes in launching and “rolling out” the Canadian Diabetes Strategy, I was surprised to learn that the Juvenile Diabetes Foundation (JDF) played a pivotal role in gaining federal commitment for the Canadian Diabetes Strategy. One person who witnessed the lobbying process first-hand told me that it is more difficult to get type 1 “on the radar screen.” Type 1 diabetes does not affect as many people as type 2 diabetes, insulin is often regarded as a cure, and no known measures can prevent its onset. By contrast, regular physical activity and good nutrition may stave off type 2 diabetes.

***“Diabetes Presents a Clear and  
Present Danger to Our Society”***

On 19 November 1999, in the middle of Diabetes Awareness Month, Canada’s Minister of Health launched the Canadian Diabetes Strategy at a press conference convened in Montreal. Since the Health Minister’s speech to launch the Canadian Diabetes Strategy reflects how he and his staff sifted available information about diabetes through the filter of the Liberal government’s priorities, mandate and perceived capabilities, it bears extensive quotation here:

As a health issue, diabetes presents a clear and present danger to our society. At least one third of the estimated 2-million people affected by this disease don’t even know they have it. That is, until it strikes them with a brutal force one day and leaves them dependent upon medication for the rest of their lives at best, and in hospital in a diabetic coma at worst.

It is a disease that affects more than the person who lives with it. It is a disease that permeates the families of those afflicted – who are forced to re-examine and substantially change their own lives in order to help their loved ones.

Diabetes is the seventh leading killer of Canadians, accounting for at least 5,500 deaths each year. But that isn’t counting the estimated 20,000 deaths a year from complications such as heart disease and kidney failure. And the toll that it takes on quality of life.

Diabetes costs the Canadian economy an estimated \$9 -billion per year, and may account for 5 to 14% of health care expenditures in Canada.

A major concern is that type 2 diabetes, often called “adult-onset,” is now three times as prevalent in Aboriginal people as in the general population. In fact, health experts are estimating that 27% of First Nations people will have type 2 diabetes within the next twenty years.

The good news is that diabetes, in most cases, can be prevented and controlled. That those family members at risk can live, thrive and survive because they can learn key lessons from their mothers, fathers, and siblings afflicted with diabetes about the importance of eating right and making regular exercise a habit. Because diabetes is very preventable. Ninety percent of all Canadians who suffer from diabetes suffer from type 2, which can generally be prevented through proper nutrition and exercise. (Rock 1999a)

Besides measures targeting “the general population” and a separate Aboriginal Diabetes Initiative, as promised in the 1999 budget, Minister Rock announced that the Canadian Diabetes Strategy would encompass a National Diabetes Surveillance System (NDSS) to improve epidemiological and cost-effectiveness data on diabetes in Canada.

Minister Rock also said,

Through the creation of the Canadian Institutes for Health Research, we are creating a modern framework to bring together all fields of research relevant to key themes and issues. Whatever the specific institutes may be once that has been decided, we know that, given the importance of this disease – and its complications – to Canadians’ health and the health care system, diabetes-relevant research will be an important component. Through the CIHR we will be able to build on the diabetes research base in our universities, health and research centres;

teaching hospitals; federal and provincial governments; voluntary and private sectors. We will be able to support and link researchers in new ways. And we will use the results of this research to inform the efforts under the Canadian Diabetes Strategy. (Rock 1999a)

The Canadian Diabetes Strategy did not dedicate funds for basic research, despite vigorous lobbying for such a commitment by the Juvenile Diabetes Foundation.

### *Behind the Scenes*

One of the main objectives of my fieldwork was to account for how diabetes became a federal “budget line” in 1999. I suspected that someone within the staff complement appointed by the Minister of Health had championed diabetes, such that it became a fully-fledged file.

In Canada, political issues become “files,” also known as “dossiers,” within governments. They outline tasks and constraints in relation to key texts (Cambrosio, Limoges, and Provonost 1990; Schacter and Haid 1999). The 1995 Royal Commission on Aboriginal Peoples final report, the 1997 Speech from the Throne, the February 1999 budget speech, the Canadian Constitution and the Canada Health Act represent key texts in the development of a diabetes file within the Canadian government. In addition to support from foundational texts, each file requires at least one well-spoken and well-positioned spokesperson to inform policy or law. Without a champion, the file will remain inchoate or stall.

After several months of “asking around” for contacts within the Health Minister’s office, I identified and then interviewed two members of his staff whose responsibilities include diabetes. One, a senior policy advisor, played a pivotal role in creating a federal diabetes file. The other became involved because she has responsibility for Aboriginal health issues.

Early in the interview with the senior policy advisor, I observed that a budget line “doesn’t happen by accident.” “There’s got to be people talking to people,” I said. “There has to be some resonance, too.”

He confirmed this: “That’s right. And the resonance is, I think, the sheer magnitude” of the problem and “the stark reality of conditions on-reserve” in particular. “That meant there was going to be some significant funding.”

I followed up by asking, “How does a picture of the stark reality of conditions on reserves become visible here?” He replied, “In part, briefings from the Department [Health Canada], but also meetings. It was generally known out there.” In response to the same question, his colleague later told me:

Well, we have pretty good relationships with AFN [Assembly of First Nations]. We get lots of intelligence from them about what is actually happening. They’re saying, ‘Look at what we’re dealing with, amputations, dialysis.’ Then the cost of medical transportation alone [borne by Health Canada]. Speaking of dialysis, it will be very, very interesting to see what happens after the 5-year period, when every province can quote you numbers [from the National Diabetes Surveillance System].

She thus implied that cost data and projections for dialysis might position diabetes centrally “on the radar screen” within provincial governments because they have responsibility for delivering health care to all but Registered Indians. The federal government transfers funds earmarked for health care to provincial coffers, but provincial governments mete these out.

In interviewing her more senior colleague, I probed the impact of the media in creating awareness about the impact of diabetes in reserve communities. I recalled that “a very large *Globe and Mail* spread on Sandy Lake” appeared in November 1998 (see Abraham 1998b), less than three months before the 1999 budget. “Now that helps some,” he said, but “people who have the Minister’s ear” wield more influence.

Then he revealed that the mass media had played a crucial role in the development of the diabetes dossier, but not at all in the way that I had anticipated: “On the one hand, you could simplistically say that Mary Tyler Moore comes to Ottawa.

This disclosure – that an American actress had kick-started federal policy on diabetes in Canada – hit me like a bombshell. I did not ask about the role played by Mary Tyler Moore in this interview, preferring to cover off other points in the limited amount of time available. But with this clue to the genesis of a federal diabetes dossier in hand, I embarked upon an investigation of when, how, and why Mary Tyler Moore wielded such influence. I will report on the results of my inquiries after summarizing what I learned in the remainder of this interview with a senior policy advisor about the policy-making process in general and Canadian diabetes policy in particular.

Suspecting that “star power” alone had not swayed the Canadian government, I continued to plumb the reasons for diabetes’ political appeal in the late 1990s. I asked about public finances, in light of heightened public concerns about government expenditures and deficits. “Well, there’s the cost issue, and yet the cost issue was not as persuasive as one might think,” this senior advisor replied, because there was already some “openness for health spending in the [1999] budget.” There were other candidates for a strategy at the time, he told me, but the Liberals went with diabetes in the end. “I think it’s fair to say that [Health Minister Rock] realized as part of the work around AIDS, breast cancer” that “the strategy approach” could work. In 1998, Minister Rock renewed AIDS and breast cancer initiatives originally established under the previous Conservative government (in 1990 and 1992, respectively).

My informants’ remarks prompted me to recall a speech that dealt with “questions of values,” which Minister Rock had delivered some months before within an enclave of prestige and privilege, the Empire Club in Toronto. I told my informant:

One of the things that I noticed in going through the Minister’s speech to the Empire Club was that he used [type 2] diabetes as an example in trying to say something about questions of values in a broader sense, not just economics.

After I prompted my informant to recollect the Empire Club speech, he noted that, with diabetes, “there is a direct link with the determinants agenda,” which is “always difficult to push.”

He meant that the epidemiology of type 2 diabetes supports the notion that health status roughly mirrors social status, due to the cumulative impact of socially-mediated physical environments and social circumstance. The “social determinants of health” approach stresses the socially-rooted causes of disease, not clinical treatment. It implies that to improve population health, social inequalities need redress. The Canadian government took a lead role internationally in health promotion with the influential 1975 “Lalonde report” (Kunitz 1987 for discussion). Nevertheless, the extent to which the social determinants of health manifest themselves in individual behaviour such as smoking and physical inactivity means that the degree to which society, through governments, can and should intervene remains contested.

Minister Rock’s speech to the Empire Club began with a rhetorical question: “Can we keep our Canadian health care system, of which we are so proud, into the new century – with an ageing population, with increased pressures, with higher costs of technology?” Minister Rock continued, “I say that we not only can, but we must, keep what has become to us an icon – an icon of what we are as a country that reflects our deepest values and commitment to each other as Canadians.” As for how monetary and social values interface, he noted, “Canadians spend \$80 -billion a year on health care, and it’s sometimes astonishing to look at how little we know about what we get for the money.” (Rock 1999b)

Later he said, “I’m the Minister of Health and not the Minister of Illness, and it’s often forgotten.” Minister Rock emphasized that “lifestyle changes” such as smoking cessation and physical activity could reduce the incidence of diabetic “complications” such as “circulatory problems with amputations and retinopathy, which is now one of the leading causes of blindness in Canada.” (Rock 1999b)

In closing, Minister Rock underscored that “the rewards of Canadian citizenship” flow from the proper investment of tax dollars: “...if the government is going to spend, it’s going to spend where there’s a return which improves the quality of life or achieves a worthwhile purpose.” (Rock 1999b)

After bringing up Minister Rock’s speech to the Empire Club in the interview with one of his senior advisors, thereby trying to place how diabetes fit within the overall thrust of federal health policy, I decided I should recapitulate the key factors that led to earmarking funds for diabetes in the 1999 budget speech:

So let me make sure that I’m understanding the skeleton of it, anyways. So leading up to the budget decisions, there is a bit of momentum building for the strategy approach. Diabetes is on the agenda for a few different reasons: Mary Tyler Moore comes to Ottawa with JDF [Juvenile Diabetes Foundation], a sense that it might resonate with the constituency, perhaps partly demographics, and that at the same time there is a very urgent picture emerging about on-reserve conditions, up to budget stage. So that’s February. So since then—

I have to admit that I was flattered when my informant cut in to congratulate me on my grasp of the genesis of the dossier: “You know, I took a course in law school called ‘active listening,’ and you have obviously taken the same course – that’s a very good summary.”

Given that the Juvenile Diabetes Foundation, particularly in the person of Mary Tyler Moore, raised the profile of diabetes such that it became a “budget line,” it is ironic that neither the 1999 federal budget nor the eventual Canadian Diabetes Strategy allocated money for basic research into diabetes. This irony was not lost on my informant. He observed, “JDF deserve a lot of credit [for lobbying for a diabetes strategy]. JDF, as you know, is mandated to fund research to find a cure.” He reported telling JDF representatives, after Minister Rock’s speech to launch the Canadian Diabetes Strategy emphasized type 2 diabetes and its

prevention, “CIHR will take care of you. Don’t worry too much if you don’t get research funds per se [under the Canadian Diabetes Strategy].”

Near the end of the interview, reflecting on the origins of the federal diabetes dossier, he said:

It’s funny. It’s a lesson in how programs actually get rolled out.  
And some of them can be distilled down into simply rumour,  
parents. And for me, it was simply meeting Mary Tyler Moore.

He also disclosed that a picture of Mary Tyler Moore, taken in Ottawa more than a year before, still graced his refrigerator at home.

### *Some Significant Ones Embody and Embrace Diabetes*

Mary Tyler Moore, who has type 1 diabetes, is best known for her lead role in the hit 1970s television series that carried her name. Her fame continues to resound, certainly in Canada. Indeed, she came to Ottawa on 2 February 1999 mainly to take part in an “inspirational women’s lecture series” entitled “Unique Lives and Experiences,” which puts the spotlight on such celebrities as Moore, Candace Bergen, and Erin Brokovitch (Martin 2001).

A radio broadcast that aired in Ottawa the day after her public lecture – and after JDF introduced Mary Tyler Moore to Prime Minister Chrétien, Minister Rock, and a coterie of their advisors – paid tribute to Mary Tyler Moore’s ability “to draw people in.” At the beginning of the segment, the reporter attributed the continued popularity of her 1970s syndicated television show to, as Moore herself has put it, her “high like-ability quotient.” Then, taking a jibe at the guest host for the day (the erstwhile leader of the right-wing Reform Party, Preston Manning), he noted that Moore had met with Canada’s Prime Minister the day before:

You know, if you’d just won that last election, you could’ve met her yesterday. She met [Prime Minister] Chrétien, she called him ‘sensitive and intelligent’ and announced that he was giving \$6-million to diabetes cure research, which was one of the causes she’s representing. (CBC Morning 1999)

I was not able to corroborate this pledge of \$6-million for diabetes research, but precisely two weeks later, Finance Minister Paul Martin's 1999 budget speech promised \$55-million earmarked for a Canada-wide diabetes strategy.

Moore has served as International Chairperson of the Juvenile Diabetes Foundation for over fifteen years. Repeatedly, through advertising campaigns and lobbying politicians directly, she has marshalled her fame, energy, and personal story in the service of JDF. Given her apparent impact on behind-closed-doors budget decisions in Canada in February 1999, I found it useful to study the text of a speech that she gave a few months later before a US Senate Appropriations Subcommittee in Washington, DC. At the end of this presentation, she saluted the senators on this committee for previous funding allocations for diabetes research and pleaded for their continued support:

Mr Chairman, you and this committee can take credit, through your past commitments to NIH, for having helped bring us to the threshold of a cure. And we at JDF have been proud to be your partners in this absolutely crucial endeavor. We know that this is a particularly difficult year for appropriations. But we cannot lose momentum. Not now that we are so close.

So, I ask you, Mr Chairman, members of the committee, look around this room once more, listen to the voices of the children who will tell you their stories today, and when you retire to your deliberations, promise to remember them, promise to remember the more than 16-million people [in the United States, including the estimated number of undiagnosed cases], who like me, have diabetes, and promise to work with the NIH to ensure that funding is provided so that all identified research opportunities in the DRWG [Diabetes Research Working Group] are explored. At a minimum, we need to be able to tell the children and their loved ones that we are investing the dollars necessary to find a cure. Thank you. (cited in Juvenile Diabetes Foundation 1999c)

In this speech, Moore affiliated herself with everyone around the world diagnosed with diabetes, and in particular with children who, like her, have type 1 diabetes. She embraces them all as kin.

The discovery that Mary Tyler Moore played heroine in the conception of the Canadian Diabetes Strategy brought to (my anthropologically-trained) mind Sahlins' ruminations about the impact of Captain Cook and his sailors on the governance of Hawaii. Sahlins wants to understand how exchange between Hawaiian commoners, especially women, and English seaman redirected history by recasting the symbolic order of people and things. He shies away from histories that revolve around heroes and villains. Yet he also insists that not all people carry the same social weight:

For heroic history, then, the effective statistical rule would be something like a Principle of the Significant One: the one who counts....

The complement of such heroic statistics is a political division of labor in cultural and historical consciousness. The time of society is calculated in dynastic genealogies, as collective history resides in royal traditions. In the state rituals and political councils of the elite, the cultural schemas are subject to manipulation and comment by specialists, such as priests and genealogists, attached to the ruling interest. (Sahlins 1985, 49)

Mary Tyler Moore, the Prime Minister of Canada, the Minister of Finance, the Minister of Health and at least one of his advisors had a hand in the birth of the Canadian Diabetes Strategy. Yet apart from talent wed to ambition and serendipity, how did these Significant Ones acquire their powers?

Cabinet ministers embody "the will of the people" in their respective ridings, and also the will of the Prime Minister. Trusted advisors extend Ministerial bodies, providing extra "eyes and ears," as it were. Following British parliamentary tradition, the Prime Minister of Canada is the leader of the party that won the most seats in the most recent election. Thus, politicians become Significant Ones largely by swaying opinion.

In JDF, one finds hopeful and impatient people, including Mary Tyler Moore, who try to attract attention and funding for their cause. Moore embodies diabetes, fame, and therefore social memory; this American actress also represents her generation, the post-WWII baby boom. Through these qualities in combination, she brought to Canada something of the touch of Midas for diabetes.

The seemingly spontaneous decision to devote funds for diabetes in the 1999 budget stemmed from months and years of behind-the-scenes effort. For example, representatives from the Juvenile Diabetes Foundation of Canada took part in the official consultation process preceding the 1999 budget (Patt 1998). Further, lobbyists could muster plenty of evidence from clinical trials, which take years to complete, and from other diabetes research projects.

### **WHITHER DIABETES? “FLESHING OUT” SCIENCE POLICY**

Diabetes researchers and organizations were generally encouraged by the 1999 federal budget, but concerns remained. An information session on the CIHR held during the 1999 CDA Professional Conference alerted me to the fact that many diabetes researchers worried that they would be neglected in the “fleshing out” of Liberal science policy. The problem of sweet blood, however, would ultimately feature prominently in the establishment of the CIHR.

#### ***Of Body Types and Body Parts***

Mainly diabetes researchers attended the information session about the CIHR held during the 1999 Canadian Diabetes Association Professional Conference, alongside a smattering of scientists who investigate other endocrine diseases. The atmosphere was tense. It immediately followed the annual general meeting of the CDA’s Clinical and Scientific Section, which I also attended. It seemed to me that most of the audience moved from that luncheon to this session.

Dr Diane Finegood chaired the session, introducing the presenters and directing subsequent questions from the floor. The presenters were Dr Peter Glynn and Dr Mark Bisby. Dr Bisby was then Director of Programs with the Medical Research Council. Dr Glynn was on the interim governing council

overseeing the creation of the CIHR. At the time, he was also Vice-Chair, External Relations Committee, Heart and Stroke Foundation of Canada; President and Chief Executive Officer of the Kingston General Hospital, Kingston, Ontario; and an adjunct professor at Queen's University in Kingston, Ontario. In a previous incarnation, he served as an Assistant Deputy Minister within the federal government. Below, I analyze remarks made by Dr Glynn and questions posed to him from the floor at this session.

Dr Glynn began with a joke that fell flat. He noted that his audience had just consumed a substantial lunch, and so promised to speak very loudly whenever saying something important. This pledge raised but a strained giggle or two. "Been there, done that," he added. He moved quickly into the substance of his presentation, an overview of the CIHR's development to that point and the timetable for the following months.

Dr Glynn noted that he served on the task force appointed by Health Minister Allan Rock that was charged with "fleshing out" the vision held by the executive director of the MRC at the time. "There was a report to the government in January [1999] and [the February 1999] budget speech basically gave us what we asked for," he reported. He underlined that the Speech from the Throne delivered the month before this presentation sent a positive signal for health researchers by emphasizing how the government might support a knowledge-based Canadian economy (see Speaker of the House 1999). He seemed to have read the words therein as so many tea-leaves:

And then to the surprise of all of us, and Mark [Bisby] will talk about that in more detail, yesterday the Prime Minister came up with *twelve hundred* research chairs. Why?

Those of you who read the *National Post*, there was an article last week on how Jean Chrétien ran into George Soros at Davos – the Davos conference in Switzerland, and basically Soros was saying, 'Canadians just chop down wood and move water and some minerals, and stuff like that.' And the Prime Minister was

quite incensed. *This* is the result of the Prime Minister getting quite incensed.

Some members of the audience chuckled at this second-hand anecdote. Dr Glynn continued to underline that these are “exciting times” and reported,

What all of us are trying to do is get it to *at least* one percent of what we spend on health care, which gets us close to a billion dollars a year for health research.

Next, he “walked through” the consultation process to determine the structure of the CIHR. “The intent is to create between ten and fifteen institutes,” he reminded the audience.

We now have proposals for between one and two hundred.

[pause] Everyone will not get their favourite institute.... And indeed, creating these ten to fifteen is going to force all of us to have different conversations, with different people, than we have ever had before. Because I can assure you, that if you stay in your own niche, that you will be left [pause] in your own niche.

He underlined that, ultimately, the Liberal government would approve CIHR structure, including the mandates of the component institutes.

Dr Glynn also emphasized that, unlike the MRC, each component institute of the CIHR would fund social as well as biomedical research on health matters, so as to promote exchange among the disciplines. For example, he proposed that findings in microbiology could reach social scientists, but only through finding new ways for social scientists to converse with microbiologists. “If one might get a just a tad absurd, maybe microbiology is just social science. It’s just about bugs, as opposed to about people,” he said. I may have been the only one in the room to find this observation intriguing, rather than wacky. But then, I was probably the only social scientist present, and surely the only anthropologist of people and things biomedical. Reviewing Dr Glynn’s remarks to prepare this chapter, I could not help but think of some provocative theorizing – contrasting laboratory studies of “homosexual” fruit flies with the ethnographic study of the French and Japanese scientists who conduct research on these anomalous flies – about the

very nature of scientific investigation (Houdart 2000). I also recalled my analysis, presented in the previous chapter, of how certain diabetes researchers understand and exploit genetic similarities between human beings and flies.

Later, to build support for partnerships (versus “part-with-*your*-money ships”) between the CIHR and disease charities such as the Canadian Diabetes Association, Dr Glynn recalled a “classic case” involving the wastage of researchers’ time and energies as peer reviewers:

[The] Heart and Stroke [Foundation of Canada] has this classic case of a room at the Chateau [Laurier – a landmark hotel adjacent to Parliament Hill in Ottawa] that had the MRC review committee in cardiovascular disease. A week later, in the *same* room, with the *same* people, Heart and Stroke had their cardiovascular review committee, reviewing *mostly* the same projects. [pause] This makes no sense. And we need to find a better way of spending *your* time.

Then Dr Glynn explained that the government would likely table the necessary legislation by November 1999. The consultation process would end a few months after that, so as to bring the CIHR into being by 1 April 2000, or less than fourteen months the after 1999 budget speech breathed life into the concept.

To lead off the question period, Dr Finegood asked how Dr Glynn envisioned “the CIHR truly implementing these words.”

Dr Glynn said in reply, “The first thing is to decide what the institutes are going to be – the ten to fifteen” and then to put the rest of the governing structure in place. He also appealed for assistance with “strategic thinking” from the CDA and its members.

Given the multitude of proposed institutes, an audience member asked:

Will [they] be centred around diseases? Around body parts, as somebody said? Or shouldn’t they be...centred around large themes that will include important diseases?

Dr Glynn urged those present to participate in the consultation process, but also to expand their horizons:

Bring us your ideas. But make them different than they used to be. Different relationships, different ways of thinking, rather than, as I keep pushing people on, thinking about diseases and body parts...

Dr Finegood then intervened as Chair, and expressed concern about expending energy and precious time to reach, in vain, the people charged with structuring the CIHR:

I don't want to get involved in something that's going to take time a huge amount of time, take time away from my research, and then be put in a drawer at the interim council's table. How do I know that if I take time, and spend a lot of time now, a get a group of people together to discuss these issues, that you'll actually listen to us?

Dr Glynn replied, slowly and calmly:

You'll be listened to. There's absolutely no doubt about that. Whether or not it will see the light of day, I can't say. [pause] But the challenge of this is that we don't know. We really are trying to create something that has not existed in the world before. It is not a replication of the NIH. This is not "bricks and mortar" institutes...

Through these and other replies, Dr Glynn tried to assuage the researchers' worries that Canada's new health research funding body might downplay diabetes generally and reject their research projects in particular.

As someone who conducts research on health matters, I can testify that the creation of the CIHR has generated anxiety and guarded optimism. A change as monumental as the CIHR, in the wake of deep budget cuts under the Liberals to the MRC and Canada's other federally-funded research granting councils, seemed destined to generate anxiety. Yet diabetes researchers had particular cause for concern. In part, their worries seemed to stem from the nature of the disease, and in part, from the low profile that diabetes has had relative to the best available guesses about its social and economic impact.

Recall that sweet blood, the hallmark of diabetes, affects the entire body, as opposed to a single organ. Type 1 diabetes illustrates this point. With the destruction of insulin-producing cells in the pancreas, sweet blood results. Using insulin to moderate blood glucose levels can reduce, but not eliminate, the risk of developing such “complications” as heart disease, eye disease and kidney disease. Type 2 diabetes may lead to these same “complications,” but due to resistance to insulin throughout the body in conjunction with malfunctioning insulin-producing cells in the pancreas.

Ironically, the systemic and long-term impact of sweet blood may dilute its profile. Diabetes is sometimes called “the silent killer” (see Adler and Kalb 2000; Elliot 2000, for example) because it contributes to cardiovascular disease – the leading cause of death in North America – and yet this association often goes unnoticed and even unrecorded in medical records and statistics. And from the point of view of people diagnosed with diabetes, the onset of cardiovascular disease, kidney failure, blindness, or other “complications” may represent *additional* health problems, rather than signs of *worsening* diabetes.

In 1999, several diabetes researchers in Canada clearly feared that an eventual Institute of Heart Health or an eventual Institute of Genetics might not fund *their* projects. Yet with fewer than fifteen institutes in the cards, an institute that would fund diabetes research *only* seemed unlikely.

### ***Targeting Diabetes***

In July 2000, Health Minister Allan Rock named the thirteen components that would make up the new CIHR (Canadian Institutes of Health Research 2000a). One of the thirteen institutes – the Institute of Nutrition, Metabolism and Diabetes – explicitly concerns diabetes (Canadian Institutes of Health Research 2000c). Its head, Dr Diane Finegood, is a diabetes researcher– the very Dr Finegood who aired doubts and concerns, captioned above, about the fate of diabetes in the CIHR. In addition, the Institute of Aboriginal People’s Health names diabetes as priority research area (Canadian Institutes of Health Research

2000b). Dr Jeff Reading, appointed to lead this institute, has considerable expertise in the epidemiology of diabetes, its complications, and associated risk factors in Aboriginal communities across Canada (see Young et al. 1999; Young et al. 2000; Reading 1999, for example).

The press release that accompanied the launch of the thirteen component institutes invoked diabetes to justify the creation and organization of the CIHR. It announced that the CIHR would instil an “integrated, multidisciplinary approach” to generating “new knowledge and its translation into improved health for Canadians, more effective health services and a strengthened health care system.” The individual institutes are supposed to work together, not at cross-purposes. The problem of sweet blood was marshalled to illustrate the value of this new approach:

Consider diabetes, which affects tens of thousands of Canadians and their families, particularly within Canada’s Aboriginal population. Its economic cost to Canada is estimated to be in excess of \$25 -billion a year. Working together, several Institutes could develop a broad, multidisciplinary research agenda to address diabetes.

Biomedical researchers would examine the molecular mechanisms of the disease, while clinical researchers would look at what treatments are most effective. Health services researchers would develop models for providing the best possible care to people with diabetes, while researchers into the health of populations would assess factors relative to diet, environment or socio-economic status that may contribute to diabetes or its devastating complications. (Canadian Institutes of Health Research 2000a)

Note that this press release estimates that diabetes costs over \$25 -billion annually, a much higher figure than the \$9 -billion figure that has circulated widely since the early 1990s.

To investigate this discrepancy, I left a voice mail message for the media contact listed on the press release, but he did not return my call. I eventually

reached another CIHR communications officer who, after “looking into it,” told me that, “to be frank,” he could not locate the source for the \$25-billion estimate. Accordingly, he said that he would revise the figure to \$9 -billion in the version of the press release archived on the CIHR web site. Why \$9-billion? Because he consulted a *Globe and Mail* supplement sponsored by the Canadian Diabetes Association (to be discussed in more detail in the next chapter), which says that diabetes and its complications “us[e] up one in seven health care dollars [in Canada], which translates into \$9-billion annually.” (Canadian Diabetes Association 2000c).

The CIHR communications officer with whom I spoke also drew attention to a press release that he had personally prepared. It announced that the CIHR and three pharmaceutical companies would provide a total of \$25-million to fund a clinical trial aiming to prevent type 2 diabetes. It also cited the president of one of the three pharmaceutical companies involved as saying that diabetes “costs anywhere from \$7 to 10 billion a year to treat in Canada alone” (Canadian Institutes of Health Research 2000d).

The chain of events above illustrates how, in snowball fashion, statistics may end up referencing new combinations of people, dollars and other things as they “migrate” across space and time from their origins. Readers will recall that the \$9-billion estimate of the global cost of diabetes in Canada equals one-tenth of the total annual estimated “financial burden” imposed by diabetes in the United States, according to a 1993 report (Ray, Wills, and Thamer 1993; Canada. Health 1999c). Many studies suggest that the number of diabetics has increased substantially, even dramatically, since then.

In February 2001, the government announced “an investment of over \$12.8-million for diabetes research across Canada, through the CIHR.” On this occasion, a Liberal Member of Parliament representing the Minister of Health said, “These research grants not only represent the Government of Canada’s ongoing commitment to diabetes, but are a strong indicator of the kind of

innovative and far-reaching research CIHR funds across the country.” (Canadian Institutes of Health Research 2001).

Thus, sweet blood featured prominently in the CIHR’s first few months of operation. Diabetes was deployed to justify the very creation of this organization, its senior staff complement includes diabetes researchers, and it has bestowed money and visibility on a series of research projects that target diabetes.

### **SUMMING UP POLITICAL RHETORIC AND POLITICAL REALITIES**

Heeding Foucault’s call to “cut off the king’s head” – to see beyond the vestiges of sovereign power – when analyzing the deployment of power under liberalism (Foucault 1994 {1978}, 638-639), micro-macro dualism stands diffused in my account of how sweet blood gained recognition as a social problem within the Canadian government during the 1990s. Unlike the sovereigns of old, who represented an order distinct from the populace over whom they ruled, Significant Ones under liberalism appear to be cut from the same cloth as their subjects. They have simply become “bigger” because they count for more human bodies and other things (after Sahlins 1963; Callon and Latour 1981). Further, when liberal subjects override, replace or discard Significant Ones, “the system” usually remains fundamentally untrammelled (cf. Sahlins 1985).

Statistical tabulations of votes, television ratings, opinion poll results aid enormously in these operations. As shown in this chapter, health professionals, bureaucrats, politicians and “even” people with sweet blood – including Mary Tyler Moore – extrapolate from statistical knowledge about populations to plot distinct genealogies and futures. By representing people and all other things as token numbers within a liberal rationality, Significant Ones gather resources unto themselves and plot their distribution (cf. Sahlins 1963; Sahlins 1985). Much authority rests with the state apparatus under liberalism, and in this sense power retains a “central tendency,” but just who occupies the state apparatus remains subject to change. Furthermore, power is not exclusive to the state apparatus. The

practice of tracking populations over time, as in opinion polls or clinical trials, underscores that “modern” governance operates through collections of “representative” individuals, whether within or without the state apparatus (see also Cambrosio and Limoges 1991; Desrosières 2000 {1993}; Epstein 1997). These representatives embody neither state nor population in miniature, as the macrocosm-microcosm imagery would suggest. Instead, individuals represent parts of populations whose typicality varies. Their differences and their similarities matter, especially in the aggregate, but also in relation to jurisdiction and mandate.

In launching the Canadian Diabetes Strategy and the Canadian Institutes of Health Research, Canada’s Minister of Health and allied officials emphasized that the federal government might aid the prevention of diabetes and its complications among members of the “general population” as well as among Aboriginal people. In keeping with the 1995 Royal Commission on Aboriginal Peoples final report and the promises made in response in the 1997 Speech from the Throne, these initiatives include Aboriginal-focused components. Aboriginal people with diabetes outnumber their non-Aboriginal counterparts by at least three to one in Canada. Further, the federal government has direct responsibility for their health and for health care. Accordingly, half of the funds allocated under the Canadian Diabetes Strategy will go to its Aboriginal Diabetes Initiative.

People with type 2 diabetes outnumber people with type 1 diabetes by about nine to one, but the ratio between type 2 diabetics with “complications” to type 1 diabetics with “complications” is lower than that. Since type 1 diabetes usually strikes before adulthood, people with type 1 diabetes usually live with the disease for most of their lives, unlike the majority of people with type 2 diabetes. Thus, “complications” set in at younger ages, on average, among people with type 1 diabetes than among people with type 2 diabetes. Fully half of diabetics living with failed kidneys have type 1 diabetes, for example (Whiteside 1999; Steele and Whiteside 1999).

When federal politicians spoke about type 1 diabetes through the 1990s and 2000, they consistently held out the hope that basic research might yield a cure, thereby preventing the disease from striking in the first place. This emphasis is consonant with the mission of the Juvenile Diabetes Foundation, “to find a cure for diabetes and its complications through the support of research.” (see Juvenile Diabetes Foundation International 2000; Juvenile Diabetes Foundation Canada 2000). The lack of attention to the prevention of complications among people with type 1 diabetes in the component of the Canadian Diabetes Strategy focusing on “the general population” also reflects how jurisdiction over health care is parcelled out between federal and provincial governments in Canada’s Constitution. The fact that the mandate to deliver health care rests with the provinces, except in the case of Registered Indians, greatly affects federal health policy.

In the “roll-out” thus far of the Canadian Diabetes Strategy, information about “healthy lifestyles” has been presented as the key to preventing type 2 diabetes and its “complications” because a balanced diet and regular exercise may help reduce their incidence (see Pan et al. 1997). Insofar as the message about the importance of a balanced diet and regular exercise applies broadly in Canadian society, circulating information about how “lifestyle” can prevent type 2 diabetes and its complications falls under the federal mandate to promote health among its citizenry.

Yet to prevent complications, people with type 2 diabetes will typically need pharmaceutical treatments to unsweeten their blood (Meltzer et al. 1998). Similarly, the prevention of “complications” among type 1 diabetes pivots on managing the sweetness of blood: measuring nutritional intake, accounting for the impact of physical activity, testing blood glucose levels frequently, and fine-tuning insulin dosage accordingly (Meltzer et al. 1998). Learning to control the sweetness of blood in these ways takes skill and effort, but this knowledge does not directly concern “a healthy lifestyle” as usually conceived because it involves health professionals providing advice tailored to individual patients:

“treatment” as opposed to “health promotion.” In Canada, the provinces reign over the former. The “jurisdiction issue” is extremely frustrating, reported an endocrinologist who currently sits on the Canadian Diabetes Strategy’s Adult Health Promotion and Prevention steering committee in an interview.

Besides promoting the prevention of (type 2) diabetes and related complications, in view of the current reliance on American data to estimate the epidemiology and the financial impact of diabetes in Canada, a Canada-wide National Diabetes Surveillance System will be set up as part of the Canadian Diabetes Strategy. The NDSS, to be discussed in greater detail in the next chapter, will pool data from provincial, and territorial governments’ health insurance plans. Thus, it will require co-operation from provincial and territorial governments, as well as from First Nations. It has secured co-operation from these parties because, “We all want the data,” explained one interviewee who has been involved in negotiating the “touchy” and “complex” issues of how, and which, users will be able to identify Registered Indians within the data base. Similarly, a provincial government representative told me in an interview, “We all need it.” In the long run, this source speculated, the NDSS might push forward “the diabetes agenda” by enhancing the capacity to answer “that famous question” in government circles, namely, “What is going on in other jurisdictions?” In other words, the NDSS will permit government officials to rate the quality and the nature of the diabetes data generated in their jurisdiction.

Prior to existing as printed numbers, populations do not – for the purposes of governance – exist. I insist on this point, because, as seen in Taylor’s rendering of the “politics of recognition,” the statistical technologies upon which populations depend for their existence themselves routinely elide recognition. “We” take them for granted, perhaps because they are part and parcel of us. Even when rendered as spoken words, even when reproduced in misleading fashion, population statistics can *claim* a paper trail leading all the way back to that population’s constituent parts: individual bodies and their parts (after Foucault 1994 {1978}, 651; Hacking 1982; Latour and Bastide 1986). In these ways,

statistics enliven and reproduce populations. Such are their very significant powers. Similar to the elaborate, enumerated displays featured in Melanesian ceremonies (Sahlins 1963; Strathern 1992a, 182; Weiner 1976), statistical arrays make people count, and they make people count differentially.

## 7. How to Feel about Sweet Blood: Accounting for the Costs of Diabetes

Why, by the year 2000, did sweet blood gain recognition as a social problem besetting Canada? To nuance the response to this question presented in the previous chapter – namely, that diabetes “hit the radar screen” – the present chapter examines the levying of such sentiments as dread, horror, pride, sympathy, and shame onto information about the toll exacted by sweet blood on individuals, families, communities, and nations.

To conjure and apportion emotion in a liberal democracy such as Canada, such diverse players as researchers, politicians, journalists, and diabetes organizations describe the impact of diabetes in personal, medical and monetary terms. The emotional freight carried by statistical knowledge about diabetes surfaces overtly in the definition of “a public health disorder” adopted in the lead paragraph of the Canadian Diabetes Association’s *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada*. Along with evidence of “a high disease burden” and “a changing burden suggesting preventability,” diabetes constitutes a “public health disorder” because of the “*fear* that things are unknown and out of control” (Meltzer et al. 1998 citing; Vinicor 1994, emphasis added). The available evidence about the association between diabetes and suffering on a mass scale is robust enough to ground fear, but also incomplete enough to heighten fear.

By examining how representations of lived experience interlace with statistics and with money to shape feelings about sweet blood, this chapter explores some implications of describing, classifying, ranking and aggregating lived experience. Accounts of suffering concomitant with diabetes have recently gained emotional salience, I will show in this chapter, by portraying the sweetness of blood in various populations as evidence *for* and *against* “development” around the world and throughout human history. Reflecting on the sweetness of

blood in human populations – past, present and future – foregrounds the patterning of coeval experience.

### LEARNING FROM HIV

Diabetes suffers from an “image problem.” Rather than resounding emotional chords, sweet blood seems banal, even to many physicians and health researchers.

Diabetes is not AIDS and it is not cancer, I was told repeatedly by diabetes professionals (in wistful and matter-of-fact tones) during fieldwork. It is difficult to imagine that a contemporary report might bear a title like “Cancer: A Serious Disease,” or “AIDS: A Public Health Problem.” But in 2000, the CDC released *Diabetes: A Serious Public Health Problem* (Centers for Disease Control and Prevention 2000), which sparked the *Newsweek* cover story featured at the outset of this thesis. Neither sweet blood nor sweet urine figures in Western “punitive and sentimental fantasies,” unlike the detection of the HIV virus or of cancerous cells (Sontag 1990 {1988}, 3). Simply put, diabetes is not a “sexy” disease. Yet, as one physician said in an interview, “To me it’s as bad a diagnosis as cancer” because “people die slowly with diabetes, they die one cell at a time.”

The distillation and commercial production of insulin in the early 1920s provided the means to stop type 1 diabetes from killing children and youth, thus diffusing dread within biomedicine and across affluent societies. Meanwhile, perhaps because it is so common among middle-aged and elderly people, type 2 diabetes has often been portrayed as a mild health problem, especially compared to type 1 diabetes. For example, students in the human genetics course that I audited as part of my fieldwork were taught that type 2 diabetes is “less severe” than type 1 diabetes. This perception extends to many physicians. A presentation at the 1998 Canadian Diabetes Association Professional Conference by Dr Stewart Harris illustrates this point. In discussing what the results of the UKPDS clinical trial imply for professional practice, Dr Harris told the assembled that “laxity for management of type 2 diabetes is no longer acceptable... So the

concepts of the ‘borderline diabetic’ or ‘just a touch of diabetes’ are no longer acceptable.”

### *Making Diabetes Visible*

When I asked a nephrologist whether the Canada-wide organ registry had increased the visibility of diabetes by highlighting links between sweet blood, kidney disease, health expenditures and suffering, “the AIDS model” reared its head. My informant agreed and stressed, “And also don’t forget that people are becoming a lot more sophisticated now in presenting their cause.” Seeking elaboration on this point, I asked, “So you see a shift there?” The reply: “Well, absolutely. Look at the lessons learnt from HIV. The impact on other health care consumers.” This informant suggested that, in the current “AIDS era,” the generation, circulation, and imbrication of information about the subjective, epidemiological, and financial impact of breast cancer, diabetes, or any other disease comprise self-conscious rhetorical tactics.

Representatives of diabetes organizations suggested to me that the high visibility accorded AIDS is particularly instructive because, similar to diabetes, AIDS deaths stem from “complications.” This similarity has not been lost on “the AIDS community.” Increasingly, I was told by two AIDS doctors, activists and physicians compare HIV with diabetes to underscore that treatments on the market today can lengthen and improve – “save” – lives.

In addition to similarities in how “the natural histories” of HIV and diabetes wend through human lives and deaths, these conditions both exhibit moral valences that distinguish “culpable” patients from “innocent” victims. Blame may escape people with type 1 diabetes or people who contract HIV from a blood transfusion. But when infection follows unprotected sex or intravenous drug use, HIV often connotes “sin.” Similarly, due to associations with corpulence and inactivity, adults with type 2 diabetes may appear to have invited trouble through gluttony, laziness, and shortcomings in willpower.

## *Anthropology's Engagements with Suffering*

The lessons brought home by the AIDS epidemic helped establish a research agenda focused on suffering in anthropology, which this chapter seeks to extend. Confronted with the global contours and variegated experience of the AIDS epidemic in the late 1980s, anthropologists elaborated the rubric of suffering to describe the transnational distribution of misfortune (Farmer and Kleinman 1989; Farmer 1992). From this perspective, AIDS constitutes a human tragedy. Yet brushes with HIV infection differ enormously, to the point that they arguably even differ in the extent to which they embody suffering (Farmer 1997).

The anthropology of suffering has broader scope than the anthropology of medical systems because violence, poverty and injustice do not equate neatly with disease or illness. Such socio-economic conditions may even give rise to disease, nor illness. While the diagnosis of disease and the experience of illness tend to prioritize curing or healing, the weighing of suffering with words or with numbers may invite proposals for social reform. “The question of social suffering brings a stubbornly moral orientation,” for it trains attention on “what political, economic and institutional power does to people, and reciprocally, how these forms of power themselves influence responses to social problems” (Kleinman, Das, and Lock 1997a, xxi, ix)

By interpolating words, pictures and numbers, “the phenomenon of suffering as an experiential domain of everyday life has been splintered into measurable attributes” (Kleinman, Das, and Lock 1997a, xxv). The practice of comparing and measuring ways to suffer, ways to *be*, sets parameters on how people grapple with the future and with the lived experience of others, often strangers. Numbers, words, maps fairly distribute sentient populations around the world, back and forth in time, as features of variegated “environments” – including nations and states – that share a measure of physical substance and of moral fibre (cf. Anderson 1991 {1983} on nationalism).

Measurement and its corollary, interpretation, may “humanize,” generate fellow feeling, by expressing the vagaries of immediate experience in standard units that symbolize bodies as interchangeable (cf. Kleinman 1995b, 95-97). Through the interpretation of statistics, people ponder the prospect of living in different sorts of bodies. It also becomes possible to fathom the notion of purchasing additional years of life, enjoyment, or health for one’s self, immediate kin, and strangers by putting dollars to different uses. Epidemiological statistics and the monetary values that they imply take on veritable “lives of their own” (after Appadurai 1986; Kopytoff 1986), and their virtual “lives” matter. Abstracted from living, breathing individual bodies and clumped together to form populations that generate value, whether at work, at rest, or in play (cf. Marx 1954 {1887}, 97-99; Povinelli 1993, 169), epidemiological statistics and corresponding dollar values die “social deaths” only when forgotten, ignored, or set aside.

The very choice of topic for this thesis indicates that the statistically-studded strategies deployed by organizations and researchers to raise alarm about sweet blood have had some measure of success. Tellingly, when I began my doctoral program, I planned to focus on breast cancer. Diabetes researchers and diabetes organizations’ senior staff regard the breast cancer activists and researchers as having successfully adapted the “the AIDS model” to suit a gender-linked variant of a more “mainstream” disease. When I disclosed that diabetes had not been my original choice for a research topic in an interview with one diabetes researcher, he noted:

Well, you know, you've jumped onto a bandwagon. Diabetes is going to come into its own. Why did the NIH [US National Institutes of Health] suddenly put *all* this money into diabetes? Well, the numbers are finally being collected, and policy-makers are looking at it, industry is looking at it, and recognizing how big a problem it is.

Right away, this remark brought to mind ethnographic research documenting “scientific bandwagons,” in which large numbers of people, laboratories, and organizations rapidly commit resources to a problem (Fujimura 1988). With

“critical mass” achieved, the resulting momentum draws in still more resources, human and nonhuman. But unlike the molecular biology “bandwagon” in cancer research documented by Fujimura, researchers who have hopped on the “diabetes bandwagon” do not necessarily endorse or deploy the same methods. Indeed, the informant cited above cannily observed that “the bandwagon effect” helps explain why I embarked upon an ethnographic study of knowledge about diabetes.

As illustrated by my own research (and Fujimura’s), the “bandwagon effect” may breach the boundaries that distinguish academic disciplines, begetting research topics in the social sciences and humanities. This thesis therefore partakes of the very *modus operandi* – the apportioning of interest based on evidence of human suffering – that I examine in this chapter. Indeed, the present thesis would have remained inconceivable without “the bandwagon effect” that currently infuses diabetes research and related public and clinical policies because this thesis seeks to discern what has powered the diabetes “bandwagon.”

### **SUFFERING IN KIND**

Diabetes gained recognition through the evocation and channelling of emotion through a variety of formal “partnerships” and instances of co-operation between national governments, non-governmental organizations, private industry, and First Nations. In each of the examples that I discuss below, the “typing” of sweet blood, the threat of “complications,” and socio-economic characteristics together serve to inflect a variety of emotions. These imbrications also underscore that sweet blood is problem that urgently needs redress. Every measure to unsweeten blood carries a monetary cost, but, it is argued, ignoring the problem will also cost money and – what is more – take a toll on human lives. Furthermore, it is argued that the problem of sweet blood stems from an economy that is as much moral as it is financial. In fact, money surfaces in these examples as a measure of morality.

### *How Sweet is “Development”*

A symposium held in 1999 alerted me to the capacity to levy emotion onto the statistical imbrication of suffering with dollars. The theme of this symposium was “Theory, Reality and Hope,” and it focused on the epidemic proportions of the problem of sweet blood among Aboriginal populations.

Dr Louis Montour of Kahnawake, a Mohawk community near Montreal, coined this three-pronged approach to redressing the problem of sweet blood upon addressing the Second International Conference on Diabetes and Indigenous Peoples, hosted by Hawaiians in 1993. The “Theory, Reality and Hope” symposium that I attended formed part of the 1999 Canadian Diabetes Association Professional Conference. A pharmaceutical company, SmithKline Beecham, sponsored this session.

After an opening prayer by a Mohawk elder, Mr Alex McComber of Kahnawake introduced Dr Jeff Reading to the assembled as a fellow Mohawk hailing from the Six Nations Iroquois Confederacy. Readers will recall from the previous chapter that, in 2000, Dr Reading was named head of the Institute of Aboriginal People’s Health under the CIHR umbrella.

In his presentation at the 1999 Canadian Diabetes Association Professional Conference, Dr Reading reviewed the epidemiology of type 2 diabetes, associated risk factors, and its “complications.” Most of the data came from the First Nations and Inuit Regional Health Survey (see Reading 1999; Young et al. 1999). Dr Reading also underscored that the principles of community ownership, control and access – “the OCA strategy” – had guided this survey from conception through analysis. This study was designed to meet the information needs of First Nations, Inuit, and Métis organizations across Canada, while remaining acceptable to individuals and communities. Health Canada funded the survey, but First Nations implemented and ultimately controlled it (see O’Neill et al. 1999).

To situate the impact of type 2 diabetes on First Nations across Canada within a global context, Dr Reading plotted the epidemiology of diabetes in terms

of a model endorsed by the WHO. “The epidemiological transition” underscores links between disease, economy, and demography, and it provides a framework for indexing “development” (see also McKeown 1976; Young 1988).

Nations start off with Stage 1, sort of Third World conditions – famine, infectious diseases, high mortality. And then they proceed with increasing wealth to Stage 2, which is a decline in infectious disease, population growth; and finally to Stage 3, which is a rise in chronic disease. Public health measures are a feature in the transition from Stage 1 to Stage 2, along with increased economic wealth.

Aboriginal people can be characterized broadly as moving from Stage 2 to Stage 3, where wealth has not kept pace with the Canadian population’s wealth. However, there has been a decline in infectious disease; there has been rapid population growth; and now we’re seeing an epidemic of chronic disease; life spans are increasing.

As Dr Reading implies, measures that secure dramatic increases in life expectancy at birth, such as improved access to food, do not keep chronic diseases such as type 2 diabetes at bay over the life-course. In fact, the ready and steady access to calories characteristic of “Westernization” increases the risk for type 2 diabetes.

In these respects, the sweetness of blood in a population indexes “development.” Increased life expectancy at birth – due to increased food security, improved sanitation, and, to more limited extent, clinical interventions – is one of the hallmarks of “development.” Reduced mortality among infants and children, in particular, has contributed to the older average age typical of “developed” compared to “developing” countries. Another sign of “development” is the reduced physical activity, such that “exercise” becomes a leisure activity. At the same time, the effects of sweet blood underscore that “development” is not a panacea; it has not (yet?) produced utopia.

In the question-and-answer session that followed Dr Reading’s presentation, the endocrinologist-epidemiologist Dr Hertzel Gerstein noted that

“all the studies that have looked at diabetes prevalence in various communities around the world do show, as you alluded to, a socio-economic gradient, with higher rates of diabetes in lower socio-economic groups.” He asked Dr Reading to elaborate on the association between socio-economic status and prevalence of type 2 diabetes in First Nations across Canada.

Dr Reading replied that that the First Nations and Inuit Regional Health Survey did not include questions about income. “But we can tag, and we have tagged, community ecological variables that look at things like potable water, housing, unemployment rates.” He continued, “But one really has to really understand that we are talking about poverty within a context of poverty.” He emphasized that the revenue streams and local environments of contemporary First Nations reflect the history of colonialism. Efforts to stem the ongoing effects of colonialism extend to data collection and analysis: “And you know, the issue of having First Nations control over data is not a grab for power. It’s a grab for an interpretation of the information that can be useful, and yet not characterize communities as being in a state of constant chaos.”

Another audience member asked about costing and modelling the economic impact of the type 2 diabetes epidemic among First Nations. In reply Dr Reading said, with resignation, “Someone once said that a health economist knows the price of everything and the value of nothing. The value of people is the true cost of this problem. The cost of no action is that people don’t get well.”

### ***“Something to Look Forward To”***

Type 2 diabetes is much more prevalent than type 1 diabetes, but type 1 diabetes is also widely regarded as a health problem that strikes far too many, far too soon. The Juvenile Diabetes Foundation portrays type 1 diabetes as burdensome, unfairly and even needlessly so. Its slogans include “The Only Remedy is a Cure,” “Insulin is Not a Cure” and “Creating a World without Diabetes.” Dial 1.800.CURE.JDF to reach the Juvenile Diabetes Foundation International and 1.877.CURE.JDF to reach the Juvenile Diabetes Foundation

Canada, invite their respective web sites. JDF emphasizes that type 1 diabetes tends to strike during childhood or adolescence. The name of the organization reflects this theme, and so does its history. Parents of children with type 1 diabetes formed the organization in 1970 to push for more diabetes research in hopes of finding the means to cure this disease.

A current public relations campaign, “Something to look forward to,” features Mary Tyler Moore with three children aged 9, 10 and 12 (see Figures 22 through 24). Guided by market research, the *pro bono* campaign emphasizes “that those who suffer from diabetes should have more to look forward to than life with an incurable disease.” The press release that launched this campaign quotes Mary Tyler Moore:

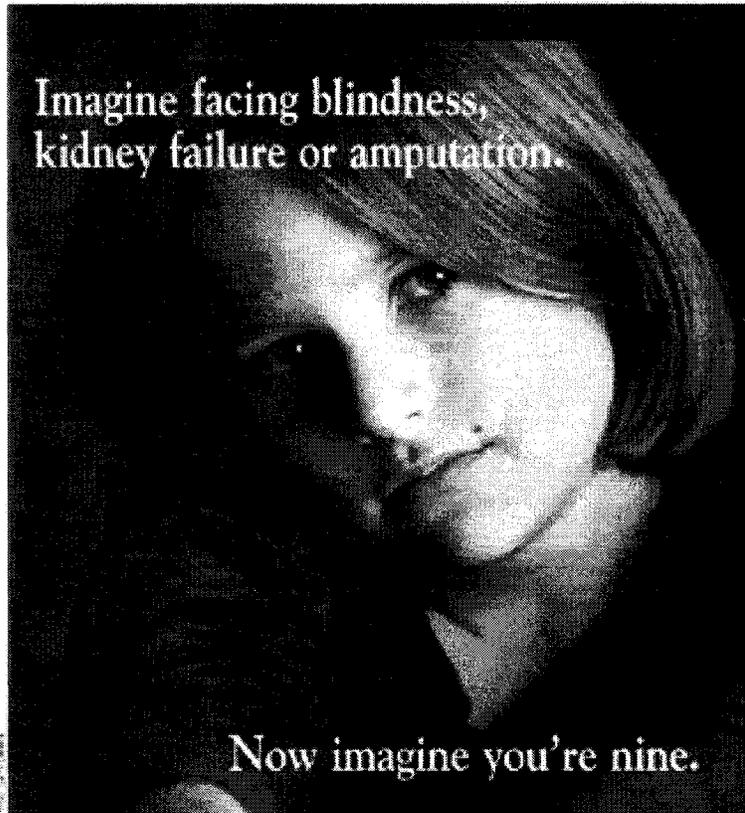
We hope this campaign will create greater awareness of diabetes. Insulin is *not* a cure, but the research funding efforts of the Juvenile Diabetes Foundation are making tremendous progress along the path toward that goal – translating research into longer, healthier lives. (Juvenile Diabetes Foundation 1998)

It also quotes the president of the advertising company that developed the campaign as saying, “It’s been an incredible experience to be able to leverage my professional livelihood to help rid the human race of this devastating disease.” Yet to underscore the overall impact of diabetes in the United States, this press release also regrouped type 1 with type 2 diabetes. It told readers: “Diabetes and its complications kill one American every three minutes. It is the leading cause of adult blindness, kidney failure and non-traumatic amputations.”

One of the children featured in the campaign introduced Hilary Rodham Clinton, then First Lady of the United States, during a “Children’s Congress” convened to lobby for more funding for diabetes research (Juvenile Diabetes Foundation 1999a). On that occasion, the First Lady announced \$120-million of federal funding for clinical trials on immune tolerance “speed the path for a cure for juvenile diabetes” (Juvenile Diabetes Foundation 1999b). A press release posted to the JDF web site contains Samantha Mandel’s remarks and the poster bearing her photograph in the “Something to look forward to” campaign. A

## Figure 22:

**“Imagine facing blindness, kidney failure or amputation. Now imagine you’re nine.”**



Kids like Samantha deserve more to look forward to than daily injections and incurable disease. Although insulin can help, it is not the cure. In fact, diabetes kills one American every three minutes. At last, there's hope. Research funded by the Juvenile Diabetes Foundation is closer than ever to a cure. But we can't do it alone. To find out how you can help, please call 1.800.JDE.CURE.



Juvenile Diabetes Foundation International  
The Diabetes Research Foundation



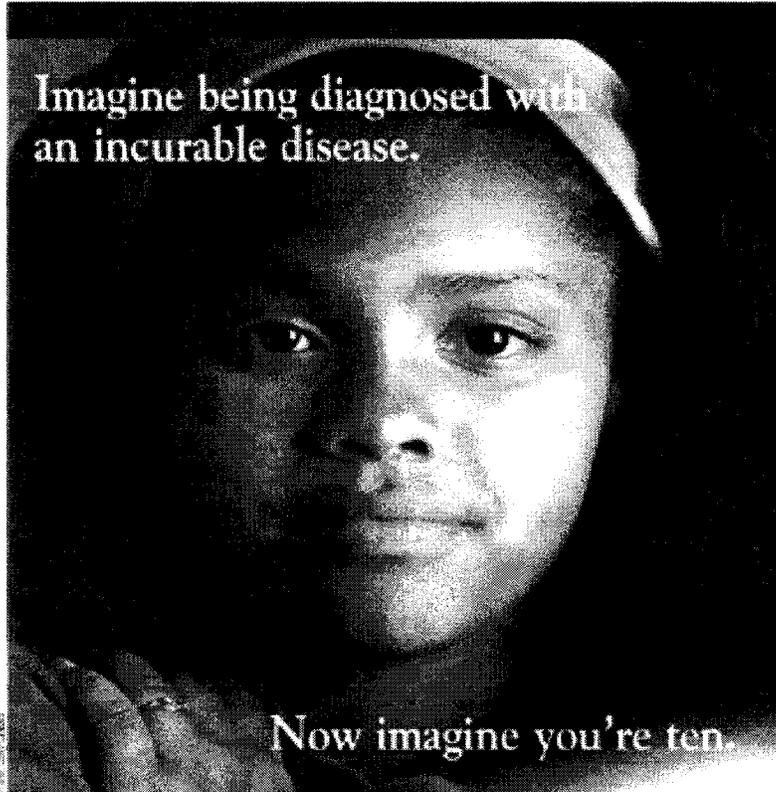
Missy Filler-Meyer  
Executive Director  
Juvenile Diabetes Foundation

Call 1.800.JDE.CURE

“Kids like Samantha deserve more to look forward than daily injections and incurable disease. Although insulin can help, it is not the cure. In fact, diabetes kills one American every three minutes. At last, there’s hope. Research funded by the Juvenile Diabetes Foundation is closer than

## Figure 23:

**“Imagine being diagnosed with an incurable disease.  
Now imagine you’re ten.”**



Kids like Jennifer deserve more to look forward to than daily injections and incurable disease. Although insulin can help, it is not the cure. In fact, diabetes kills one American every three minutes. At last, there's hope. Research funded by the Juvenile Diabetes Foundation is closer than ever to a cure. But we can't do it alone. To find out how you can help, please call 1.800.JDF.CURE.



Juvenile Diabetes Foundation International  
The Diabetes Research Foundation



Mary Tyler Moore  
International Diabetes Foundation  
President, Juvenile Diabetes Foundation

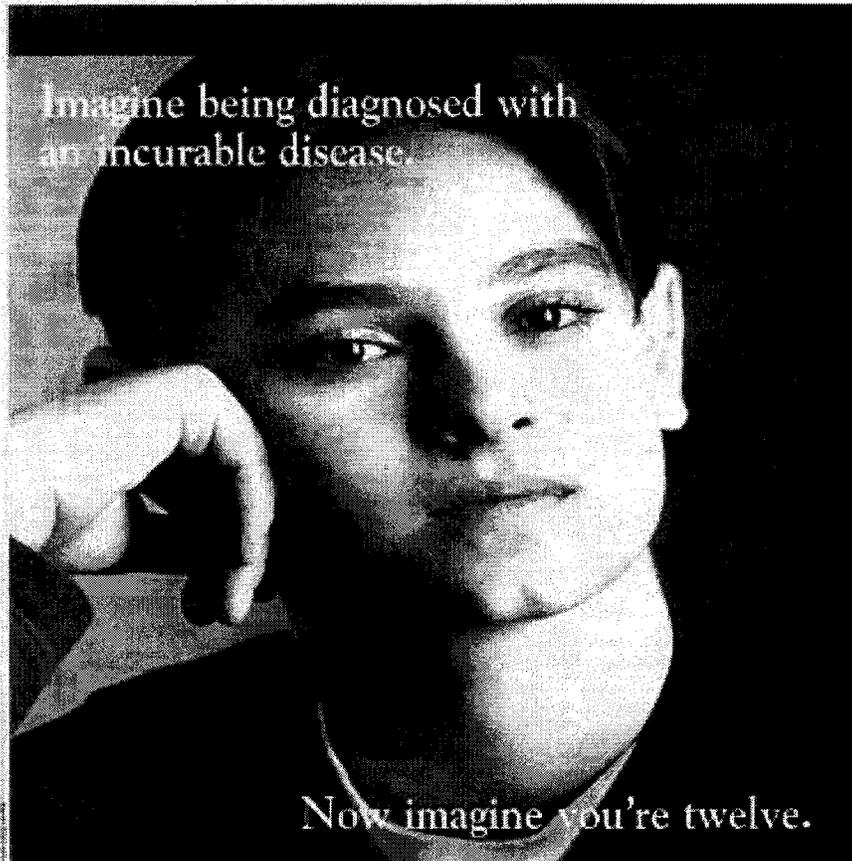
Call 1.800.JDF.CURE

“Kids like Jennifer deserve more to look forward than daily injections and incurable disease. Although insulin can help, it is not the cure. In fact, diabetes kills one American every three minutes. At last, there’s hope. Research funded by the Juvenile Diabetes Foundation is closer than ever to a cure. But we can’t do it alone. To find out you can help, please call 1-800-JDF-CURE.” —Mary Tyler Moore, International

Chairman Juvenile Diabetes Foundation

## Figure 24:

**“Imagine being diagnosed with an incurable disease.  
Now imagine you’re twelve.”**



Kids like Willy deserve more to look forward to than daily injections and incurable disease. Although insulin can help, it is not the cure. In fact, diabetes kills one American every three minutes.

At last, there's hope. Research funded by the Juvenile Diabetes Foundation is closer than ever to a cure. But we can't do it alone. To find out how you can help, please call 1.800.JDF.CURE.



Juvenile Diabetes Foundation International  
The Diabetes Research Foundation



Mary Tyler Moore  
International Chairman  
Juvenile Diabetes Foundation

Call 1.800.JDF.CURE

**“Kids like Willy deserve more to look forward than daily injections and incurable disease. Although insulin can help, it is not the cure. In fact, diabetes kills one American every three minutes. At last, there's hope. Research funded by the Juvenile Diabetes Foundation is closer than ever to a cure. But we can't do it alone. To find out you can help, please call 1-800-JDF-CURE.” —Mary Tyler Moore, International Chairman Juvenile Diabetes Foundation**

photograph of Samantha Mandel standing at a podium, Hilary Clinton at one side and Mary Tyler Moore on the other, also graces this press release. To lend further support to the “Children’s Congress,” Oscar-winning musicians composed a theme song entitled, “Promise to remember me” (Juvenile Diabetes Foundation 1999c).

### *Think Globally, Act Locally*

In 1989, the World Health Organization (WHO) adopted a resolution urging public health action to prevent and control diabetes. To raise the profile of diabetes, the WHO and the International Diabetes Federation proclaimed 14 November as World Diabetes Day and November as International Diabetes Month for the first time in 1990. As shown in the previous chapter, rhetoric about diabetes surged in the Canadian House of Commons during the 1990s, and much of the rhetoric centred on the proclamation of Diabetes Month and Diabetes Day.

Throughout November, International Diabetes Federation member associations such as the Canadian Diabetes Association focus on driving home impact of diabetes locally, but within a global frame of reference. The International Diabetes Federation and the WHO set this global frame of reference by choosing a theme, packaging related statistics, and issuing press releases. The themes chosen for World Diabetes Day in the late 1990s – the “seriousness of diabetes” in 1997, “equality” in 1998, and “the human and economic costs of diabetes” in 1999 – suggest that diabetes still suffers from an “image problem.” To help counter this perceived problem, the WHO and the International Diabetes Federation have forged forces with other “partners” to feed both the spirit of competition and the spirit of co-operation among nation states.

During fieldwork, a contact within Health Canada drew my attention to an editorial in the *Bulletin of the World Health Organization*. In it, the WHO’s Officer for Diabetes Mellitus highlighted survey results (published in that issue), indicating the profile of diabetes in ministries of health across the Americas. The editorial stressed that “regional partnerships” and their evaluation could

strengthen the capacity to prevent and control diabetes. It also underscored that such partnerships were in evidence in some countries and in some regions only (King 1999).

To gauge progress on diabetes-related public policy, the survey cited in this editorial used the *Diabetes Declaration of the Americas* as an evaluation framework (White and Nanan 1999). The *Diabetes Declaration of the Americas*, “a regional strategy for diabetes control and a guide for national program development, ” emerged from a meeting held in 1996. Representatives of the WHO’s subsidiary, the Pan American Health Organization (PAHO), the International Diabetes Federation, diabetes organizations from across the Americas, the private sector, individuals with diabetes, and representatives of national ministries of health congregated in Puerto Rico for this meeting. Five pharmaceutical companies picked up the tab. To exaggerate ever so slightly, the ink on the *Diabetes Declaration of the Americas* had barely dried when the head of PAHO publicly challenged member countries to implement its recommendations (Alleyne 1996). The *St Vincent Declaration for Diabetes Care and Research in Europe*, which “led to sustained activity in many European countries aimed at improving quality of care for persons with diabetes,” provided inspiration and a benchmark for the Americas. It came out of a similar meeting held a few years previously in St Vincent, Italy.

A document released by Health Canada in 1999 found that Canada had yet to fully implement its four “minimum essential national targets” set out in the *Declaration of Diabetes in the Americas* (Canada. Health 1999c, 52-53). This document, entitled *Diabetes in Canada: National Statistics and Opportunities for Improved Surveillance, Prevention and Control*, entered circulation after the budget promised government action on diabetes but a few months before the launch of the Canadian Diabetes Strategy. Since diabetes does not affect Canada alone, the document suggested that “it is perhaps best to learn from international experience.” The *Diabetes Declaration of the Americas* provides a “logical approach” to alleviating the “increasing burden on Canadians.” Failure to live up

to its standards, the document also points out, would constitute failure on a broad front in health policy: “It is becoming no longer acceptable to fund disease prevention and control programs without knowing the present status of the disease and the planned outcome of the intervention.”

*Diabetes in Canada* reported that the Diabetes Council of Canada provides “a national focal point for diabetes program development,” the first of the four objectives enshrined in the *Declaration of Diabetes in the Americas*. The other three objectives, however, remained incomplete. The proposed Canada-wide National Diabetes Surveillance System (NDSS) would fulfil the second target, “national surveillance.” The third target, “a national strategic plan for prevention and control,” was being “discussed” when this document went to press. Meeting the fourth objective, “national and local targets based on epidemiologic and resource estimates,” would clearly require “a functional national surveillance system and a well-coordinated prevention and control strategy.”

While the 1996 *Diabetes Declaration of the Americas* did not immediately, nor directly, establish diabetes as Canadian health policy target, it did help prime the federal bureaucratic apparatus to consider the merits of diabetes surveillance, prevention, and control. International promotion of Canada’s reputation for population health and for quality health care occasioned rhetoric about diabetes policy. The humble tone of the 1999 Health Canada document captioned above contrasts sharply with the note of national pride sounded by Health Canada at an international meeting on diabetes convened shortly after the *Diabetes Declaration of the Americas* came into being.

In September 1996, at a meeting of PAHO’s directing council in Washington, DC, a Health Canada representative commended PAHO for endorsing *Diabetes Declaration of the Americas*. According to his speaking notes, “Canada agrees fully with the public health, social and economic importance of effective diabetes prevention and control.” Therefore, “Canada supports the *Diabetes Declaration of the Americas*.” The notes also indicated that “Canada

recognizes diabetes as a national health priority, and is in the process of developing a diabetes prevention and control strategy.”

His notes recorded examples of successful “collaboration” between Health Canada and provincial governments, the Canadian Diabetes Association, the National Aboriginal Diabetes Association, and the Assembly of First Nations to prevent and control diabetes. In particular, the Assembly for First Nations includes a diabetes officer in its staff complement thanks to funding from Health Canada. In addition, Health Canada provided financial support for international conference on diabetes and indigenous peoples held in Winnipeg, Manitoba in 1995. He could say, “We urge other members of PAHO to also adopt diabetes as a health priority,” and, “We look forward to sharing expertise and working collaboratively with other members of PAHO to advance our mutual goal of improving diabetes prevention and control.” In such diplomatically competitive ways, he was to position Canada as an exemplary model, possessed of technical skills, compassion, an admirably rational distribution of resources, and the spirit of co-operation.

### ***“Diabetes: The Millennium Bug”***

Three “special marketing supplements” on diabetes, published in Canada during November 2000, drew upon “home-grown” and WHO statistics to argue that the “staggering” impact of diabetes has local and global dimensions.

On 1 November 2000, the Canadian Diabetes Association sponsored a supplemental section in the *Globe and Mail* (Canadian Diabetes Association 2000a). On 11 November 2000, the Quebec Diabetes Association sponsored special sections in *La Presse*, the French-language newspaper with the largest circulation in North America, as well as in the English-language *Montreal Gazette* (Association du diabète du Québec 2000; Quebec Diabetes Association 2000).

The *Globe and Mail*, *La Presse*, and *Montreal Gazette* supplements each included paid advertising for pharmacies, pharmaceutical manufacturers, optometrists, and medical supply companies. In addition, pharmaceutical funds

sponsored a full-page advertisement on erectile dysfunction on behalf of the Canadian Male Sexual Health Council in the *Globe and Mail* supplement.

The Quebec Diabetes Association English-language supplement was translated word-for-word from the French version. It ran under the title, “Diabetes: The Millennium Bug” (*«Diabète: Le bogue du millénaire»*). The Y2K computer problem pales in comparison to diabetes, this title implies – and by November 2000, readers knew full well that most anticipated Y2K problems did not materialize, whether despite or because of all the advance warnings. The opening paragraph reported the number of people thought to have diabetes in Quebec (half a million, or 6% of the population). And the problem spreads beyond “our province,” the text continued. Given the high current prevalence rates in industrialized countries and in some developing countries, the WHO estimates that 145-million people around the world have diabetes, and it predicts that the total population of people with diabetes world-wide “will rise to an alarming 300-million by 2025.” Nevertheless, “epidemiological studies are still in preliminary stages.” As many as 40% of people with diabetes “are not aware of their condition,” which compromises estimates of prevalence. The estimated impact on mortality rates and health care expenditures also receives mention in the supplement. Yet the social and economic impact of diabetes is greater still, the text explains. “Unemployment, loss of autonomy, family crisis, divorce, commercial and personal bankruptcy” are among its more personal effects.

Another banner on the first page of the “Millennium Bug” special section read, “It can happen to anybody!” – and to substantiate this message, it listed 17 famous people who developed diabetes, among them Mary Tyler Moore. The list included a few names that some readers might not recognize, Raymond Bouchard and Gaston L’Heureux among them. “Who has never heard of Raymond Bouchard?” This question appeared on an inside page of the section, which emphasized that people with both type 1 and with type 2 diabetes must “cope with the disease in their daily activities.” It revealed that Raymond Bouchard, whose lead television roles “have made an impression on a whole generation of Quebec

viewers,” has type 1 diabetes. It also disclosed that Gaston L’Heureux, who hosts a French-language television show devoted to fine wines and cheese, has type 2 diabetes. The latter “had to be hospitalized with hyperglycemia before he finally realized the seriousness of the disease.”

These two *Québécois* stars regularly lend their time and goodwill to the Quebec Diabetes Association. For example, Raymond Bouchard’s photograph and the slogan, “Together, we can conquer diabetes” (*«Grâce à vous, vaincre le diabète, c’est possible»*) adorn a donation box placed near the cash register in the corner store that I frequent in Montreal. Every time I pick up milk, beer, or potato chips, I can direct my change to the Quebec Diabetes Association.

The November 2000 *Globe and Mail* supplement rehearsed the epidemiology of diabetes world-wide (using WHO statistics), showcased Canadian research as a source of hope, and portrayed the Canadian Diabetes Association as a responsive organization. The front page contained three headlines:

- Impact of disease staggering: Diabetes is already a \$9-billion financial burden in Canada;
- Canadian research making inroads: Alberta team at centre of a breakthrough but much work remains to be done;
- Statistics devastating for Aboriginal peoples: Explosive rise of the disease in Aboriginal community.

The lead article on the impact of diabetes included the global estimated and projected diabetes prevalence calculated by the WHO and cited above. The bottom corner of the first page announced other stories that readers would find in the supplement:

- Clinical Practice Guidelines
- Taking action
- National Diabetes Strategy
- Impact of donations
- Lifestyle choices
- Diabetes camps

- Team diabetes

Below, to draw out further similarities and differences in how diabetes organizations promote the apportioning of sentiment and dollars, and to underscore that their campaigns all deploy the common strategy of personifying statistics, I examine printed materials produced as part of the current Canadian Diabetes Association public awareness campaign.

### ***“Help Someone You Know”***

Instead of mustering Significant Ones, a key tactic deployed by the Juvenile Diabetes Foundation and the Quebec Diabetes Association, the Canadian Diabetes Association chose to profile five “unknowns” in its current public awareness campaign. “Help someone you know,” it urges. As suggested by this slogan, the campaign asked members of the public to recall people already known to them who have diabetes. Another slogan currently in use, “Know who to turn to,” depicts the CDA and affiliated professionals as sources of credible information and emotional support.

The booklet and the print advertisements produced for the “Help someone you know” campaign deploy portray a handful of people as archetypes. Entitled *The Case For Your Support*, the booklet was designed to encourage donations. It depicts five people with diabetes in words and in photographs. These portraits state first names and occupational status, and sometimes age and ethnic origins too. Three out of these five people also appear in print advertisements. The other two other print advertisements feature diabetes professionals (a researcher and a dietician), identified by their full respective names. None of the campaign materials specify place of residence.

As with the earlier “over 45” CDA campaign, which was discussed in Chapter 3, the “Help someone you know” print advertisements appear at the discretion of media outlets. Canadian magazines and newspapers can fill unsold advertising space with a wide variety of public service announcements. The CDA must compete against other charities, other worthy causes, for public visibility. To

reach the public, these “public service” advertisements must first strike newspaper or magazine employees as worthy and engaging.

“Sheila,” a white “senior citizen,” is the first person with diabetes depicted in the booklet. Recently diagnosed with type 2 diabetes, she reports,

The most difficult thing for me about having diabetes is controlling the times when I eat and keeping to a schedule. On the other hand, diabetes has gotten me feeling healthier because it has encouraged me to eat better – no more junk food – and to get back into tai chi.

The caption for the print advertisement featuring her reads, “I was always tired, always thirsty. Thank goodness I knew the warning signs.” (See Figure 25).

Next the booklet introduces “James”: white, seemingly in his 20s, and recently diagnosed with type 1 diabetes. He wants readers of the booklet to know:

I love being a fireman. It’s the best thing that ever happened to me. When I was diagnosed with diabetes, I was really worried. There was a question of whether I’d be allowed to return to active duty.

“Luckily, his employers are supportive,” reports the booklet. “They understand that diabetes can be managed and does not necessarily undermine one’s ability to work.” Others have not fared so well on the job and in other spheres. “Sometimes people with diabetes are unfairly denied access to such things as health, life or travel insurance, a driver’s licence or a mortgage.” The booklet lists some advocacy struggles in involving the CDA. “James” did not feature in a print advertisement produced for this campaign.

“Bernie,” of First Nations ancestry, appears after “James” in the booklet. “For Bernie, diabetes was a wake-up call,” it reports. Currently, he is applying his counselling skills in diabetes prevention workshops that incorporate “traditional healing from his culture,” the booklet continues. Via the booklet, he offers some advice:

**Figure 25:**

**“Thank goodness I knew the warning signs.”**

**“I was always  
tired, always  
thirsty. Thank  
goodness  
I knew the  
warning signs.”**

Sheila, newly  
retired



**HELP SOMEONE YOU KNOW.  
CALL 1-800-BANTING**

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DIABETES  
ASSOCIATION** | **ASSOCIATION  
CANADIENNE  
DU DIABÈTE**

[www.diabetes.ca](http://www.diabetes.ca)

I'd caution anyone who, like me, is in a high-risk group to take better care of themselves and get tested for diabetes. I nearly lost my sight before my diabetes was caught.

The quote included on the print advertisement directly references his First Nations origins. "Traditions are a big part of my culture. Unfortunately, so is diabetes," it reads (see Figure 26).

"Jody" follows "Bernie" in the booklet. Initially, the "idea of daily injections made the 10-year-old particularly anxious," the booklet reports. But "with the help she and her parents received from diabetes educators, Jody was able to overcome her fears." In fact, "Jody's parents proudly describe her as a role model because she is managing so well." Her plans for the future include diabetes, partly because she hopes to help vanquish the disease, reports the booklet:

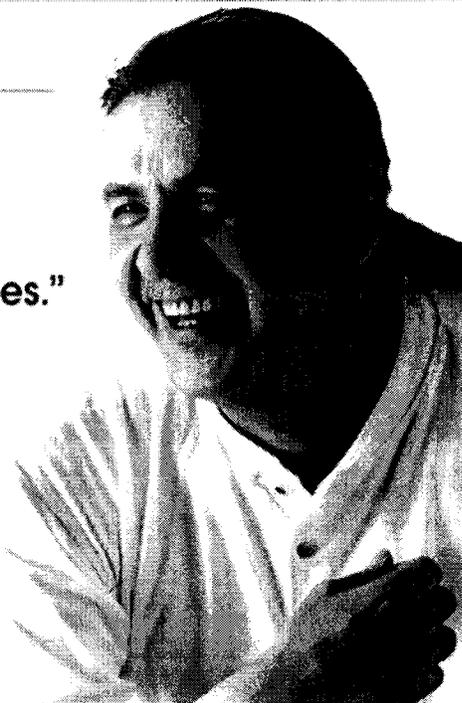
When I grow up, I want to be a diabetes researcher. I know what diabetes feels like and want there to be a cure. I'd like to be part of that.

The text accompanying the photograph of Jody (depicted with her parents and a sibling in a family portrait) in the booklet draws attention to CDA publications that target children and teenagers with diabetes and that target their parents. It also highlights summer camps designed to "help children learn to live with diabetes." The print advertisement featuring "Jody" emphasizes the support received from the CDA. "I'm doing okay, but I wish I didn't have diabetes. The people at the CDA make it easier," she is shown saying (Figure 27). Another print advertisement also underscores this message (Figure 28). It features a dietician saying, "When diabetes enters your life, you need someone to turn to. Call the Canadian Diabetes Association."

After profiling "Jody" and how CDA supports families, the booklet emphasized the CDA's role in funding research, which has improved "management methods" and "is also moving us closer to a cure." It profiled a black professional. "Lenny" says:

**Figure 26:**

**“Traditions are a big part of my culture. Unfortunately, so is diabetes.”**



**“Traditions are a  
big part of my culture.  
Unfortunately, so is diabetes.”**

Bernie, First Nations counsellor

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ASSOCIATION** | **ASSOCIATION  
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DU DIABÈTE**

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## Figure 27:

**“I wish I didn’t have diabetes.”**

**“I’m doing okay, but I wish I didn’t  
have diabetes. The people at  
CDA make it easier.”**

Jody, aged 10

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CALL 1-800-BANTING**



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## Figure 28:

**“Someone to turn to.”**

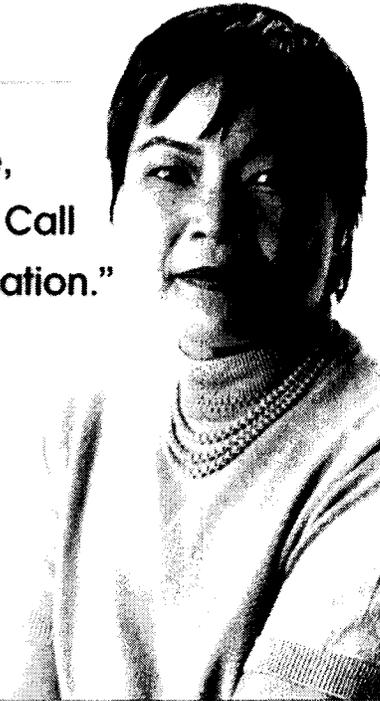
**“When diabetes enters your life,  
you need someone to turn to. Call  
the Canadian Diabetes Association.”**

Carol Seto, dietitian

**HELP SOMEONE YOU KNOW.  
CALL 1-800-BANTING**

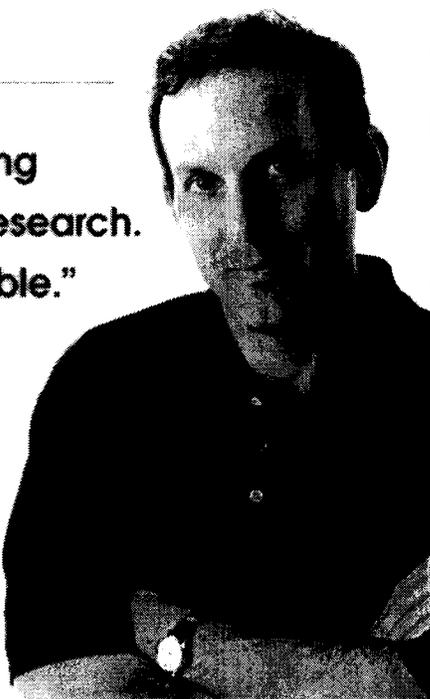


[www.diabetes.ca](http://www.diabetes.ca)



**Figure 29:**

**“Beating diabetes and treating diabetes both depend on research.”**



**“Beating diabetes and treating diabetes both depend on research. CDA funding makes it possible.”**

Dr. Daniel Drucker, research scientist

**HELP SOMEONE YOU KNOW.  
CALL 1-800-BANTING**

 **CANADIAN  
DIABETES  
ASSOCIATION** | **ASSOCIATION  
CANADIENNE  
DU DIABÈTE**

[www.diabetes.ca](http://www.diabetes.ca)

I work for a brokerage firm. Things can get pretty crazy working so closely with the markets. I'll start skipping meals and get the shakes. I'm learning to be more careful about that. After all, I've seen at least seven of my uncles and aunts die from diabetes.

That's not something you easily forget.

Like “James” the firefighter, “Lenny” the stockbroker did not appear in a print advertisement. Instead, the print advertisement focusing on research featured Dr Daniel Drucker saying, “Beating diabetes and treating diabetes both depend on research. CDA funding makes it possible.” (See Figure 29.)

Noting the emphasis on improving life for people with diabetes in the current CDA campaign, partly but not entirely through biomedical research, I recalled an interview in which I was told that the JDF stands for “hope” while the CDA stands for “cope.” Both JDF and CDA portray diabetes as the cause of much suffering and as a taxing disease to treat – especially if “complications” set in. Yet while the current JDF campaign indeed focuses squarely on the hope for a cure for sweet blood, the CDA has chosen to highlight how “quality of life” could improve in the here and now. Therefore, the research ambitions voiced by 10-year-old “Jody,” to help find a cure for diabetes, do not figure front and centre in the print advertisements for the current CDA campaign.

### ***“The Goose that Lays the Golden Egg”***

In an ideal world, diabetes would not exist. At the very least, its precise demographic and financial reach would be known – the better to predict, plan and prevent. Yet untold numbers of type 2 diabetics remain diagnosed. Nobody knows how often people diagnosed with diabetes meet with their doctors, nor for what reasons. Similarly, it is currently impossible to know why and how often people with diabetes enter hospitals, nor how long they stay. Therefore, the true prevalence and impact of “complications,” even among diagnosed diabetics, is not known. Neither are the associated financial costs. The pleasure and use of such knowledge is denied governments, diabetes organizations, and administrators.

In theory, governments in Canada could track “complications” and many associated health care expenditures for the entire country because all Canadian citizens qualify for publicly-funded insurance to cover physician visits and hospital services. No wonder, then, that Dr Stewart Harris described the National Diabetes Surveillance System (NDSS) as “the envy of Ottawa,” as “something we can take great pride in,” and as a world benchmark at the 2000 Canadian Diabetes Association Professional Conference in Halifax, Nova Scotia. He made these remarks while kicking off a session devoted to the NDSS.

He provided the following rationale for this venture:

As I'm sure most of you are aware, we don't really have good data in Canada as to the extent of diabetes, related complications, and therefore when we are trying to make projections, in terms of numbers and health care costs or programs, it's very difficult. We currently have to rely on self-report surveys; mortality data, which we all know is terribly out of date and not all that accurate; hospital discharge data; and extrapolation data from our cousins to the South.

That Canadians must divide American prevalence and cost estimates by ten to fathom the impact of diabetes in their own country seems frankly embarrassing, Dr Harris implied.

Dr Harris also underlined that the NDSS is a model program because it represents “a true partnership, a marvellous collaboration” between a host of governmental bodies and non-governmental organizations. They include the Canadian Diabetes Association, the Assembly of First Nations, Health Canada, Statistics Canada, the Canadian Institutes for Health Research, and Smith Kline Beecham, “the pioneering sponsor.” Given frictions between federal and certain provincial governments in Canada over health care, Dr Harris noted “all provincial and territorial governments, and I underline all,” have chosen to participate in the NDSS venture. “Although the data will ultimately come to Ottawa, the data collection and ownership of the data is very local. And this was a very key issue in facilitating buy-in and co-operation of the provinces, territories

and Aboriginal groups,” he added. The identification of Registered Indians in the NDSS database is a contentious issue because data ownership, control and access have become articulated to self-governance aspirations – a point already registered in this chapter, courtesy of Dr Reading, and to which I will return shortly.

Following an opening presentation by Dr Harris, the national technical director for the NDSS, Dr Robert James, provided a detailed explanation of the structure of the NDSS. Dr James focused on the powerful base unit of the NDSS – the Annual Person-Level Summary File (APLS), or Yearly Epidemiologic Summary File (YESS). He reported that he and his colleagues have referred to it as the “golden nugget” or “the goose that lays the golden egg.” Presumably, the “golden egg” is the data that can be extracted from this file. Each of these files will include basic demographic information for each individual with publicly-funded health insurance (that is, virtually the whole Canadian population); it will enumerate and describe each use of the publicly-financed health care system; and it will distinguish among people diagnosed with type 1 and type 2 diabetes, people diagnosed with one or more diabetic “complications,” and people without these diagnoses.

Highlighting that virtually everyone in the room would have such a file in the NDSS, he hastened to reassure audience members that *their* privacy would remain intact:

What I want to emphasize, because I think people are appropriately concerned about what happens to their health data, is that...nothing new has in a sense happened to your health data, other than it's now being used to tell a public health story. Your public health [care] data is not being sold; it's not being transferred out into the wilds of the internet.

After stripping names and exact place of residence, the NDSS will publish each individual's allotment of health and share of health care expenditures in a form that will permit the aggregation of all manner of suffering, and their tidy organization into kinds.

Dr Jamie Blanchard, currently at the University of Manitoba but until recently the province of Manitoba's chief epidemiologist, made the third and final presentation in the panel devoted to the NDSS. He presented examples drawn from Manitoba "to illustrate how surveillance data can be used to assist in the development of appropriate public health strategies for diabetes." His presentation demonstrated how statistical analyses regroup individual health records in the data set into various "kinds," including people with type 2 diabetes, people with household incomes below a certain threshold, people who died in a given year, and so on. For example, he showed marked variation in dialysis initiation and below-the-knee amputations across different regions of Manitoba, and he showed that poorer people seem more likely to become dialysis patients and amputees in that province. Based on such data, he made dire forecasts about the future impact of diabetes on the Canadian health care system.

Immediately following Dr Blanchard's presentation, Dr Sara Meltzer, who co-chaired the steering committee for the CDA's *1998 Clinical Practice Guidelines for the Management of Diabetes in Canada*, observed:

A lot of the data that we're working with is obviously data that doctors write... Now the Americans are working hard to improve the quality of what's written in the [physician's] office, and trying to do the coding a bit better. And I just wonder if as we move along in this process, should that be an area we should work on?

She also expressed concern about inconsistent coding practices in hospital settings.

Dr James replied:

You'll never have an epidemiologist say that the quality of the data captured shouldn't be improved. So the first point [regarding codes for physician visits], I heartily endorse.

With respect to the second point about missing diagnoses, the way that the Manitoba Rule works and the way that the NDSS will work is that once you're seen to have diabetes, that sticks

with you for the rest of your life. So if we miss someone on a single hospitalization, that's in some sense OK, because either we picked them up on a previous hospitalization or from their previous doctor visits, or we'll see that person having diabetes in the weeks or months ahead as they leave the hospital and go back to their physicians' offices....

[B]ecause we use the physician *and* the hospital data, and the attribution *sticks* for the rest of the life course after the person's initially identified [with diabetes], I think we've done as much as we can do with validity and confidence to redress this. Again, anything to improve the quality of data I'm all for. Thank you.

Thus, once “typed” as having diabetes, any “hits” to the health care system in that and all subsequent years become associated with sweet blood, even if the record for a particular procedure or appointment does not identify the patient as having diabetes.

Another audience member, who did not identify himself, pressed Dr Blanchard on how to interpret “opportunity gaps”:

Jamie, if those variations were plotted not in regions in Manitoba, but, I don't know, in world countries, and you had China there and you had Canada there. The differences in dialysis rates would be different for very different reasons. There might not be dialysis available in some areas. So you know, you showed the socio-economic data. That was one factor, but I'm sure that there's others, and many others that people in this room could posit could that explain those variations.... I just have the suspicion that diabetes care in Manitoba may be a little more uniform and advanced than in other provinces and perhaps cities in our country. And any further comments on that?

Thus, this audience member underscored that the provision of medical care might indicate a more highly developed health care system, *or* it might indicate a relative lack of development, including inefficiencies in resource allocation.

In his response to these observations, Dr Blanchard agreed that higher initiation rates might reflect better access to dialysis, or “poor access to other kinds of care,” including timely diagnosis. The NDSS will raise, but not entirely resolve, such questions, he predicted. That is, he agreed that disparities in health care procedures do not equate directly with health inequalities. In “developed” countries such as Canada, routine dialysis or amputations might well correlate with low income, but not in “developing” countries where such procedures tend to be rare indeed.

The question-and-answer period also included a testimony on how the NDSS might both induce and harness horror in provincial capitals across Canada. Dr Keith Dawson said:

Just a quick commendation. Obviously this new approach, which has been well organized, is having a tremendous impact already just in our own province of British Columbia. When Jamie came out and presented that to the Minister, it had a dramatic impact. Because they just looked at the figures and they're just horrified. He presented the data related to British Columbia and the ministers all sat up and took notice and immediately embarked on a diabetes strategy planning program. So it's very impressive how this data is going to help us all to improve the care.

Then Dr Dawson observed that expenditures related to “complications” have proved much higher than anticipated:

Jamie and I have done something together on the dollar cost of diabetes care, and he mentioned that. The fact that's staggering is the cost of *all* the [diabetes-specific] care that we administer as doctors, nurses, etc. is one-fifth. It's tiny compared to the costs of all the other problems of diabetes. Cardiovascular care [for diabetics] is just lethal by comparison. What's very surprising is the cost of renal care, renal dialysis, etc [for diabetics]. What we – I – always thought was huge is a very small proportion of the total cost of care for diabetes in Canada.

Finally, but “not to criticize,” Dr Dawson asked, “And what about impaired glucose tolerance, impaired fasting glucose? This would be a major public health strategy to further address.”

As explained in Chapter 3, impaired glucose tolerance and impaired fasting glucose are biomedical categories used to describe people who test negative for diabetes, but whose blood is still abnormally sweet. Impaired glucose tolerance is identified using the OGTT and impaired fasting glucose is detected using the FPG test. Members of these groups may be at high risk for developing diabetes and related “complications.” As discussed in Chapter 4, Dr Gerstein’s research on “dysglycemia” suggests that blood that is sweeter than the norm, but not sweet enough to diagnose diabetes, correlates with cardiovascular disease. In calling upon the architects of the NDSS to tag people with impaired glucose tolerance or impaired fasting glucose, Dr Dawson implied that to capture fully the impact of sweet blood, and to redress this impact, it would be necessary to detect and monitor these “sub-clinical” populations.

There are “huge institutional laboratories across our country that do the vast majority of work,” Dr Dawson continued. “If they were urged to provide their data based on a public health [insurance] number of an individual, they could contribute majorly [*sic.*] to this impaired glucose tolerance identification, or impaired fasting glucose.”

Dr James said that Dr Dawson raised “an excellent point.” Dr James then elaborated on the value of including fine-grained measures of the sweetness of blood in the NDSS:

I know that in Alberta they’re looking at linking in laboratory data on an individual basis. So that you can now imagine attaching or creating a data base that’s not just organized around physician diagnoses, but also around laboratory results. And actually get a gradation in terms of outcomes and costs according to glycated hemoglobin, [also known as hemoglobin A<sub>1C</sub>, this blood test is used to monitor the degree of “control” among diagnosed diabetics] things like that, etc. So I think that the

power of this is that it's an individually, it's an individual-specific database upon which you can add all sorts of other things.

Dr Blanchard said:

I would only add that Statistics Canada is going to be doing this nationally-representative survey with biological samples, and some measure of glycemic control will be part of that. It will be a very large sample.

The presentations and the contributions by audience members in this session highlight the significance of comparisons, which, in turn, hinge upon fine-grained portraits of particular jurisdictions (the United States, British Columbia, Manitoba, its regional health boards). The more they conjure emotion (pride, shame, horror, outrage), the more political weight such comparisons may carry.

### **HONOURS AND SHAME**

Until now in this chapter, I have examined efforts by diabetes researchers, diabetes charities, and allied organizations (WHO, PAHO, and pharmaceutical manufacturers, for example) to invest diabetes with greater emotional appeal. Below, I consider three instances in which Canadian journalists adopted their main message – that diabetes has grave effects, which concerted human effort could lessen and perhaps remove. These journalists made “the diabetes message” their own by linking diabetes and diabetes research to such rousing themes in Canada as the fraying public health care system, the importance of developing a “knowledge-based economy,” inequality in “life chances,” and how governments should address such inequalities. In these ways, they encourage “national feeling.” Analytically, this state of affairs underscores that the newspaper and corollaries, such as the televised newscast, play crucial roles in shaping civic politics under liberalism (Anderson 1991 {1983}, 33-36).

Liberal rhetoric about improvement may surfeit pride and shame in circular fashion, recent media coverage of diabetes in Canada suggests. The first media item discussed below trumpets success in diabetes research, bolstering regional and national pride; but it also suggests that matters could improve, and

therefore, that “excessive” pride is shameful. The other two media items focus on the failure to achieve equitable “human development” across Canada. More specifically, they fasten upon how the sweetness of blood indexes a “quality of life” gulf separating “your average Registered Indian” from “your average Canadian.”

### *Trans-National Excitement and Provincial Pride*

In addition to the appeals to sympathy and conscience that feature prominently in their “Something to Look Forward To” public awareness campaign, JDF representatives have sought to convert the excitement, respect, hope, and pride associated with successful research projects into yet more money for diabetes research. A *Globe and Mail* story about a significant breakthrough announced by diabetes researchers based in the province of Alberta highlighted JDF’s role in distributing money around the world for research into diabetes. In doing so, the *Globe and Mail* also highlighted the role of JDF in apportioning emotion, the better to combat diabetes (Foss 2000a). Readers of the *Globe and Mail* across Canada would know that Alberta’s “healthy” economy is steeped in fossil fuels; some might also know that the Alberta government has adopted several policies – including funding for health research – designed to diversify the economy and increase its “knowledge base.”

“Diabetes Cured in Lab Rats,” the headline read. The lead paragraph reported that Canadian and Korean researchers had “cured rats and mice of their diabetes by tricking their bodies into making an insulinlike substance.” The next three paragraphs read:

It’s the world’s first gene therapy to treat Type 1 diabetes successfully in animals, and it could be ready for clinical trials on humans as early as 2006, said its lead Canadian researcher, University of Calgary immunologist Dr. Ji-Won Yoon. If it proves effective in people, the new treatment would allow those suffering with the disease to forego constant insulin

needles, pumps and sprays in favour of a single, long-lasting and tolerable treatment.

The therapy may also ultimately help the burgeoning numbers of those with Type 2 diabetes – a form of the disease that develops in later life and is associated with diet and lifestyle.

Thus, the journalist portrayed the diabetes as the source of suffering – not least because of the insulin regime required to maintain life among people with type 1 diabetes – that genetic research might eliminate. Further, the journalist explains, people with the most common and increasingly prevalent form of diabetes, type 2 diabetes, might also benefit from this genetic therapy. She hints, but does not specify, that many people with type 2 diabetes use insulin. By highlighting that a certain “diet and lifestyle” increases the risk for type 2 diabetes, the journalist underscores that much of the suffering concomitant with diabetes – including its very onset – has its roots in (depending on the reader’s political views) individual choices, socioeconomic conditions, or some combination of the two.

A sidebar to the story, entitled “Research dollars pay off,” put the spotlight on the wisdom of JDF investing in Albertan researchers:

A \$116-million annual research budget has paid off handsomely this year for the international Juvenile Diabetes Foundation – but nowhere more so than in Canada where powerhouse Alberta diabetes researchers have parlayed just over \$2-million of that global investment into world-beating breakthroughs.

The sidebar then quoted the president and chief executive officer of JDF Canada as saying, “We are very excited, naturally, with the results out of Alberta particularly.” But he cautioned the *Globe and Mail* reporter, and she in turn cautioned readers, that even these breakthroughs do not constitute cures. “We have to raise more money because this is the stage where they [the researchers] need funding,” the JDF spokesperson underlined. In other words, pride in recent accomplishments by Albertan researchers will not pay for next year’s research, nor save human lives. It is implied that readers may help generate more pride, and maybe a cure, by reaching for their wallets.

The sidebar also presented an annotated chronology of key findings announced by diabetes researchers based in Alberta during 2000, culminating with the story of the day:

- May, 2000: University of Alberta researchers announce that they have reversed diabetes in eight people for more than a year following islet [insulin-producing] cell transplants [from cadaver pancreases into the livers of the type 1 diabetics] followed with [anti-rejection] drug therapy. Research is led by Dr Ray Rajotte and surgeon Dr. James Shapiro. Their work is subsequently published in the *New England Journal of Medicine*.
- August, 2000: Pere Santamaria, a microbiology and infectious diseases researcher at the University of Calgary, discovers how white blood cells cause inflammation that leads to destruction of insulin-producing cells in the pancreas. The research is published in *Nature*.
- November, 2000: University of Calgary's Dr. Ji-Won Yoon and Korean scientists report in *Nature* on using a novel gene therapy to cure diabetes in mice and rats.

The above-captioned pronouncements illustrate how provincial pride, passion, and heartfelt dreams may help generate, and combine with, heaps of money through viscous transnational networks. This money buys “tricks” played out in the bodies of mice, rats and – most prized of all – people.

***“How Appallingly the First Nations People are Being Treated”:  
National(ist) Debates***

In stark contrast to the glowing November 2000 *Globe and Mail* story discussed above, a documentary televised across Canada in March 2000 painted a shameful picture of the impact of sweet blood among First Nations and on government budgets. The documentary reserved the sting of its critique for the federal government and the provincial government of Manitoba, while portraying “average Canadians” as complicit in how sweet blood affects First Nations, partly out of an ignorance that the documentary sought to dispel. Government policies intertwine with the contours of the type 2 diabetes epidemic, gobbling tax dollars

to cover the diabetes-related health care needs of “Registered Indians.” Yet their suffering continues unabated, explained the documentary (Sherran 2000).

I first learned of this documentary while watching the 10 o’clock evening newscast on the Canadian Broadcasting Corporation’s main (that is, non-cable) television network. Headlines and breaking stories dominate the first half-hour of this newscast (called “The National”) while the second half (called “The National Magazine”) aims to add depth to the public knowledge about current affairs. On 1 March 2000, the headlines included an announcement that commanded my full attention: that night’s edition of the “National Magazine” would feature “a full-edition” documentary about “a Native community in northern Manitoba with a devastating rate of diabetes.” A preview followed. It featured an unidentified Aboriginal person saying, “I can’t even walk two blocks”; a reporter saying, “What these people do to survive”; and an unidentified white physician saying, “Sometimes I close my office door and cry. Why isn’t anybody listening?” My civic identity collapsed into the exigencies of fieldwork: frantically, I racked my apartment for a videocassette and fetched a notebook. Later, I learned that I could buy a transcript of the program for \$15, and so I did.

To lead off the National Magazine that night, the host said, “Tonight: medical refugees,” and then the program cut to a physician, later identified as Dr Richard Smith, saying, “The people of Canada and the government do not realize how appallingly the First Nations people are being treated.” A few seconds later, the host underscored the contrast between the health care issues facing “the general population” and those facing residents of reserves and other “remote communities.”

In recent months, this program has given a lot of attention to what many consider the crisis in Canada’s health care: the lack of beds, the overwhelmed emergency staff; the push towards privatization. Tonight, we look at a grim northern problem, a situation unique to remote communities; many are reserves, places without emergency rooms, hospitals or even running water. But what they do have is sick people. In this full-edition

[25-minute] documentary, the CBC's Reg Sherren looks at what the desperately ill must do to survive. Their choice: fight or flight.

As the documentary began in earnest, reporter Reg Sherren introduced the issues by introducing Jack Harper, a diabetic recently diagnosed with end-stage renal disease:

On a warm February day, Jack Harper makes his way through Winnipeg to an appointment he really can't afford to miss. Twice a week, every week, he must be plugged into a machine that's keeping him alive. Dialysis does what Jack can't do anymore. Over the next four hours, his blood is cleaned and pumped back through his system. It gives him three more days before his next appointment with the machine.

Next, the documentary quotes Jack Harper, who underscored that he must come to Winnipeg to meet his need for dialysis, and that coerced dislocation causes emotional pain: "When the doctors first told me that I had to be on that machine, my wife was devastated. Being away from the family was the most devastating of all."

Then the reporter marshalled words and video footage to convey the social and geographic distance separating viewers in southern Canada from Jack Harper's home community:

When it's over, Jack will head home to his family – but home is not here. Home is hundreds of kilometres north, deep in the Canadian Shield on the wooded shores of Island Lake. Close to 10,000 Oji-Cree live on four reserves, a people whose ancestral heritage comes from the Ojibiwa and the Cree.

The people who live in settlements that dot the shoreline of Island Lake have access to such amenities as satellite television and automobiles, but not running water, hospital beds, or dialysis machines. Such privations stand out because so many residents have diabetes. The images and narration underscore that deprivation has a particular complexion in Island Lake, one that differs from the embodiment of poverty in southern Canada:

You see satellite dishes and new vehicles, but what you don't see are some of the most basic human needs: there are no sewer pumps; there is no running water. Water is extracted from communal pumps when they're not frozen, and hauled home in plastic buckets.

What people so have, what many of them share with Jack Harper, is a medical problem that is claiming more lives every year. The diabetes rate up here is four times the national average. Every year more of those affected must leave; travelling over 700 kilometres south to the city [of Winnipeg]. Because there is no hospital here, there are no dialysis machines. For the people who are getting sicker, what there is here is the fear; the fear that they will be the next ones forced to pack up and leave behind everything they've ever known just to try to stay alive.

To bring home the impact of diabetes on members of Island Lake bands, the camera and narration follow Jack Harper off the plane and into the warm embrace of a man introduced as his brother:

Jack [Harper] comes from a long line of diabetics. Of his 16 brothers and sisters, only two have escaped the disease. His brother Harry, here to meet him [at the local landing strip], was struck blind by diabetes. But rather than move to the city, the brothers chose to stay here.

Later, the reporter explains that type 2 diabetes "is usually caused by diet and exercise but studies have revealed the Oji-Cree are also genetically predisposed to developing the disease." Readers will glean that biological samples provided by residents of the Oji-Cree community of Sandy Lake, Ontario yielded the genetic findings in question. "Island Lake is the first place in the world where children [under age 15] were found afflicted [with type 2 diabetes]," the documentary reports (see Dean, Mundy, and Moffatt 1992). Reinforcing the complex interplay between "the environment," genetic endowment, and diabetes, the documentary reported that "barely 50 years ago, the disease was virtually unknown in native

communities.... But when Western foods arrived, their systems just could not cope.”

To highlight the contribution of Western colonization to the type 2 diabetes epidemic among Island Lake residents, the camera follows a nurse on a house call while the narrator tells viewers:

Today nurse Bertha Flett arrives to test two of the young girls from this household. One of the girls has elevated sugar levels in her blood. If they remain high, her family will have to closely monitor diet and exercise. But in northern communities like these, feeding a family of nine a healthy diet is not easy. Especially when Western ideas and food have all but replaced traditional ways. All the food now is shipped from the south; most of it is expensive.... Most of the year, many fresh foods simply aren't available or affordable.

While “Western ideas and food” abound, biomedicine is in short supply. “There is no permanent doctor,” so different ones are flown up four days per week, and the nursing station is short-staffed.

The “Fight or Flight” documentary reported that the Canadian government covers about 7,000 trips annually by Island Lake band members to Winnipeg for medical appointments and procedures. “This year alone, the federal government will spend \$6-million on medical flights from Island Lake – \$6-million many feel would be better spent on facilities which are desperately needed here.” The narrator continued:

But the people living here aren't holding their breath. They say, ‘Why would a federal government that won't even provide running water want to provide a hospital or dialysis?’ Ironically, the lack of running water is one of the reasons cited by government officials as why dialysis units can't be installed. It's also why being diabetic and living up north can be so difficult. Proper sanitation and hygiene are critical: an infection can easily end in amputation.

To substantiate Jack Harper's on-camera statement, "They're forcing me to relocate," the documentary reviews how federal jurisdiction over the delivery of health care to Registered Indians interlocks with Winnipeg's income maintenance program, which the provincial and federal government help fund:

Jack wonders how long he can escape being sentenced to the city. Ninety days after he began dialysis, the federal government stopped paying for his travel. By then, it expects him to have moved to Winnipeg and transferred to city welfare. Instead, his family is spending \$1,200 of their own money for Jack to travel back and forth. But after five months, the family's savings are gone.

His brother Harry Wood has faced and fought the same dilemma. "Harry doesn't need dialysis, but he's gone through heart attacks, an amputation and the loss of his sight." He resists permanent relocation to "the bright lights" of Winnipeg because he fears every "every conceivable disaster" would befall him and his family there, "including myself living in slums where there is loneliness, trauma, things that are not being told."

In a later segment, Harry Wood explained that, in part, he steadfastly refuses permanent dislocation to Winnipeg out of a sense of duty and as part of a political strategy. "I have to live here and use this disability to highlight, strategically, on what can and should happen, because there are number of people who are going to be blind, amputees, and the list goes on and on," he said. About 500-odd members of Island Lake bands have ended up on "dialysis row" in the city of Winnipeg. "Fight or Flight" introduced viewers to a handful of these "medical refugees."

The documentary also featured interviews with Health Canada bureaucrats and with provincial politicians about the Island Lake situation. Manitoba's Minister of Health said:

Let's throw away the rulebook and let's try to do something to move this thing forward. There's been jurisdictional problems;

there's been turf wars. There's been – there's been neglect, and there's a huge health and social problem up there.

The provincial government decides where to locate dialysis machines, and not one reserve in Manitoba has one. A federal official explained, “We would have to negotiate the exact amount of the contribution with the province.”

Harry Wood was among those who voiced doubts that a dialysis machine, or other desired fruits of modernity, would reach Island Lake any time soon. In a clip placed within the seconds of the documentary's end, he appealed to viewers' sense of morality by invoking a paper trail laden with broken promises:

All the days of my natural life I've worked in the political arena. I had proposals after proposals. I can prove that a hospital was promised. I negotiated personally along with politicians of Island Lake to have a general hospital in the Island Lake [region]. That never materialized. In the meantime, we're suffering, we're dying. Do you think those people have a conscience? That's the question you should ask yourself.

After the documentary drew to a close, the National Magazine's host added “a sad footnote.” He reported, “Last night in Winnipeg, one of the people featured in our report, Harry Wood, suddenly collapsed and died. He was in the city [Winnipeg] on band council business.”

The next day, Bev Desjarlais, who represents the federal riding containing Island Lake for the left-leaning New Democratic Party (NDP), rose in the Canadian House of Commons during Question Period. She portrayed Island Lake as emblematic of the suffering currently endured by Aboriginal people across Canada. Further, she blamed past and present federal policies for their suffering. In this light, it bears noting that the NDP has never formed a federal government, but the province of Manitoba had a NDP government at the time. She stated:

Mr Speaker, the failing health of our Aboriginal peoples is a direct result of the life they were forced into by Canadian government policy. Last night CBC [the Canadian Broadcasting Corporation] told Canadians from coast to coast about the crisis

in Island Lake. Those same conditions exist in numerous First Nation communities.

Arguing that the federal Liberals have handled Aboriginal affairs most callously, she provided as evidence allocations under the 1999 federal budget (the one that promised an Aboriginal Diabetes Initiative as part of a Canadian Diabetes Strategy). She alleged:

The budget ignored the Aboriginal health crisis. There was not one new dollar for First Nations' health care. How long do Aboriginal people have to wait before the government does something? How many must die? (Desjarlais 2000)

In his response, the Minister of Health, Allan Rock, defended his government's record by reporting that the 1999 budget contained measures to improve health and health care for Aboriginal peoples. He did not mention diabetes specifically, but the dollar figure that he gave includes the funds earmarked for an Aboriginal Diabetes Initiative:

Mr Speaker, last year's budget dedicated over \$200-million to Aboriginal health and added the capacity of Health Canada to develop home and community care on reserves in First Nation communities and to increase the number of medical personnel, including nurses. It's very difficult, as the member will know, to engage the services of doctors and nurses to provide services in far-flung communities in the north. We are doing the best we can. We are improving our services and we will work toward meeting those health care needs. (Rock 2000b)

Just over two months later, the documentary about the impact of diabetes in Island Lake aired across in French, and Minister Rock was again obliged to field questions about health care for First Nations. On that occasion, R  al M  nard, of the pro-sovereignty Bloc Qu  b  cois party, marshalled the Island Lake situation to suggest that the federal Liberal's pledge to monitor health care delivery by provincial governments oversteps its bounds and its competencies:

Mr Speaker, this week, we heard on the news about the terrible situation on the Island Lake reserve, where Aboriginals have no

health care services at all, when it is up to federal Minister of Health to see that they do. How can a minister who is unable to properly discharge his reduced health care responsibilities claim to control what is going on in Canadian provinces? What nerve. (Ménard 2000a, official translation of the original French)

Earlier that day, Ménard had charged that budget cuts compromised the federal government's authority to enforce the terms of the Canada Health Act, and he called upon the federal government to restore federal-provincial transfers to the 1993-1994 levels (Ménard 2000b).

Rather than engage Ménard's allegation that the federal government lacked both the capacity and the mandate to monitor the delivery of health care by Quebec and the other provinces, Minister Rock elected to defend his government's record on Aboriginal health matters:

Mr Speaker, we are working closely with Aboriginal communities to make the necessary health care services available. When one has responsibilities involving very remote regions, it is always difficult. However, we are working with communities to meet our responsibilities. (Rock 2000a, official translation of the original French)

Ménard continued to press his concern with jurisdiction over health care: he challenged the Minister to channel money earmarked for monitoring the delivery of health care by Canada's provinces to improve health care for Aboriginal people instead:

Mr Speaker, instead of spending \$4-million to establish a network of federal health inspectors to spy on the provinces, would the Minister of Health not be better advised to use that same amount to do what he is paid to do and provide Aboriginals with decent health care? That is his job. It is what he is supposed to do and what he should be looking after. (Ménard 2000b, official translation of the original French)

Replied the Minister of Health, “We spend over \$1-billion annually to ensure health care services are available to Aboriginals on First Nations territory.” (Rock 2000a, official translation of the original French)

The “Fight or Flight” documentary prompted both NDP and Bloc Québécois members of parliament to recruit the suffering wrought by sweet blood in Island Lake in calling the governing Liberals to account. Through its mismanagement, federal government has caused suffering and institutionalized inequality, they argue. For both the NDP and the Bloc, lack of access to dialysis and other health care services in the immediate vicinity of Island Lake bespeaks federal incompetence and misplaced priorities writ large. The NDP member also explicitly roots the problem of sweet blood in the ongoing history of colonization. In his replies to their questions, the Minister of Health did not contest that the quality of health services available to reserve residents could stand improvement. But, he stressed, geography and market forces limit the federal government’s capacity to act.

The contents of the documentary and the response that it engendered from politicians illustrate how narratives, numbers, images, and categories (“type 2 diabetes,” “dialysis patient,” “Registered Indian”) comprise emotional hinges that permit voters and politicians to somehow fathom suffering – and participate in its management – from a distance. Notably, neither the NDP nor the Bloc member named diabetes and neither did Canada’s Minister of Health. The far-reaching effects of sweet blood on First Nations so epitomized a series of problems that the word “diabetes” never surfaced in these parliamentary exchanges. Rather than viewing diabetes as the cause of ill, the “Fight or Flight” documentary and the parliamentary debates that it sparked focused on the social and economic roots of suffering among First Nations in Canada.

***“Our Silence Hurts Native People”: A National Disgrace of International Proportions***

In the previous chapter, I drew attention to a *Toronto Star* editorial arguing that Aboriginal affairs still fail to register on “Ottawa’s political radar screen.” This argument pivots upon international benchmarks, I will show below.

The editorial in question, entitled “Our silence hurts native people,” appeared in April 2000, between the English and the French telecasts of the “Fight of Flight” documentary. It accompanied a feature story on the current and projected impact of type 2 diabetes on Aboriginal peoples across Canada, focusing on the reserve community of Sandy Lake as an extreme case that portends ill on a massive scale. The feature began on the first page with a colour photograph, printed above the fold, featuring a woman in the local cemetery at dawn. It continued over three full pages in the front section. This article formed part of a week-long series, dubbed “Lost People,” about “the problems facing native reserves.”

The *Toronto Star* feature underscored that residents of Sandy Lake had “third-highest known diabetes rate in the world” (Elliot 2000). As readers will recall, the Northern Ontario reserve community of Sandy Lake has the third-highest age-adjusted prevalence of type 2 diabetes ever reported, after the Pima of Arizona and the Nauru people of the South Pacific (Harris et al. 1997). As this ordering suggests, type 2 diabetes has exploded among Indigenous peoples the world over. Indeed, the *Toronto Star* feature took pains to explain that the sweet blood epidemic has reached deep into the Aboriginal population in Canada, well beyond Sandy Lake. “As many as half [of] Canada’s natives over the age of 50 have diabetes; the general native population is affected at about six times the national average,” the article reported.

The companion editorial began by reiterating a quote that appeared near the end of the feature article published that day:

‘What is more morally reprehensible,’ asks epidemiologist [Jeff] Reading. ‘To cause something or to turn a blind eye to it? The net result is the same.’ (Toronto Star 2000)

Then the editorial stated that the impact of type 2 diabetes on First Nations in Canada reflects broader, deeper problems that rival those found in “developing” countries and that have registered as such internationally:

Reading was talking about the epidemic of diabetes among native Canadians....

But he could just as easily have been talking about any aspect of life on Canada’s native reserves: the mass unemployment, inadequate housing, widespread abuse of alcohol and drugs, lack of proper health care, a non-functioning education system, or the high suicide rates that led the World Health Organization to rank conditions on native reserves in Canada 63<sup>rd</sup> in the world, below Mexico or Thailand. (Toronto Star 2000)

The WHO has reported that Canada’s “750,000 native people suffer poor health conditions and indicators show they are at greater risk for tuberculosis, diabetes, suicide, violent death and alcohol-related illness and injury than the general population” (Alderete 1999). The WHO has not, however, ranked the average standard of living on “Indian Reserves” in Canada in comparison with the average standard of living in other countries.

As the editorial correctly pointed out, the United Nations has condemned Canada for permitting “a gross disparity” to persist between the low standard of living on reserves compared with the high standard of living enjoyed, on average, by other members of the society (United Nations 1998). But, like the WHO, the UN has *not* ranked the average standard of living on “Indian Reserves” in Canada against the standard of living found in other countries.

Yet the editorial did not pull the “63<sup>rd</sup> in the world” ranking from thin air. In 1998, using the Human Development Index endorsed by the United Nations, two researchers working for a federal ministry – Indian and Northern Affairs Canada – calculated that, on average, the standard of living on “Indian Reserves”

across Canada would rank 63<sup>rd</sup> in the world (see Figure 30). “Registered Indians” living off-reserve fared somewhat better, occupying an interstice between Panama and Poland, but still ranked well below Canada’s position atop the UN’s 1998 report card.

In March 2001, at a conference billed as “Canada No. 1, or Not Really?” that focused on the validity and the political importance of these rankings, I discussed the *Toronto Star* editorial proclaiming that the WHO had ranked on-reserve living conditions 63<sup>rd</sup> in the world. My panel that included one of the two researchers who performed these calculations. He marvelled at how these figures acquire “lives of their own.” He gave as an example a cartoon appeared on the *Globe and Mail*’s editorial page (see Figure 31). It trumpeted the pithy finding that on-reserve living conditions ranked below the United Arab Emirates; but it also pilloried what such calculations might achieve, and it questioned the completeness of the data set. For as hinted in the cartoon, many First Nations refuse on political grounds to participate in the Canadian census, upon which the contrast in HDI scores for “Registered Indians” compared with “the general population” relies.

The UN relies on the highest recorded national average life expectancy at birth—that of Japan—to judge the relative health of people in countries around the world. Yet this average on its own is defined as inadequate as a universal standard. The national average life expectancy at birth in Japan is 80 years, while it is 82.5 years for Japanese women (Murray 1996). The UN, however, has determined that 85 is the maximum possible national average life expectancy at birth (United Nations Development Program 2000, 269). It ranks countries by how close they come to this longevity ideal.

The UN does not equate longevity alone with “quality of life,” for it also regards knowledge and money as significant determinants, and measures, of health and well-being. The UN uses a formula that converts average life expectancy at birth, average level of education (years of schooling, percentage of adults with basic literacy), and gross domestic product per capita each into score

**Figure 30:**

**Select 1998 Human Development Index scores**

HDI Rank		HDI Score	Real GDP per Capita (in US \$)	Educational Attainment	Life Expectancy at Birth
1	<b>Canada</b>	0.932	19,320	0.93	77.2
2	Switzerland	0.931	21,780	0.92	77.8
34	Russian Federation	0.858	6,930	0.86	70.0
	<b>Off-Reserve Registered Indians</b>	<b>0.857</b>	<b>9,905</b>	<b>0.82</b>	<b>72.2</b>
35	Trinidad and Tobago	0.855	8,380	0.83	70.9
47	Panama	0.816	4,910	0.75	72.7
	<b>Registered Indians</b>	<b>0.815</b>	<b>8,890</b>	<b>0.72</b>	<b>70.7</b>
48	Poland	0.815	4,500	0.84	71.5
62	United Arab Emirates	0.744	17,000	0.56	70.8
	<b>On-Reserve Registered Indians</b>	<b>0.761</b>	<b>6,542</b>	<b>0.62</b>	<b>67.6</b>
63	Brazil	0.756	5,240	0.64	65.8

- Adapted from source file: Beavon, Dan, and Martin Cooke. 1998. Measuring the Well-being of First Nations Peoples. Paper read at Annual Policy Research Conference, October, at Winnipeg, Manitoba.

Figure 31:  
Editorializing the "Quality of Life" Gap  
between "Registered Indians" and "The General Population" in Canada

BETWEEN POLLS

By Michael Eddenden



Source: Globe and Mail, 22 November 1998.

between zero and one. The HDI score equals the sum of longevity, knowledge, and money scores.

Money figures in the HDI as “a surrogate for all the dimensions of human development” that longevity and education data do not capture but that underpin “a decent standard of living” (United Nations Development Program 2000, 269). Since the UN presumes that individuals benefit as cash circulates through the economy, it takes GDP per capita – not average personal income – as its base unit. According to the UN, “maximum human development” can be purchased with \$40,000 US per capita per year, converted into local currency. It considers the equivalent of what \$100 US per capita can purchase as the bare minimum. Assuming a finite amount of money can purchase a “respectable level of human development,” it discounts, using a logarithmic formula, per capita GDP as it approaches \$40,000 US. At the equivalent of US \$22,480, Canada’s GDP per capita in 1999 represented 77% of what the United States rang up (\$29,010). Once submitted to the logarithmic formula, Canada scored 0.90 on the HDI’s income component, while the United States scored 0.95.

The *Globe and Mail* cartoon that ridicules the exercise of calculating HDI scores to measure the living conditions on “Indian Reserves” in Canada extends a veritable local tradition. Because Canada scored highest on the HDI for seven consecutive years, from 1992 through 2000, media items routinely discuss the United Nation’s annual *Human Development Report* and its Human Development Index (see, for example, Watson 2000; Simpson 1999; *Globe and Mail* 1999; Barber 1999; Owens 2000).

Many pundits have advised modesty about Canada’s consistently high showing because the HDI consists of averages, and averages conceal variation. To have ranked highest on the HDI from 1992 through 1999 may be a feather in Canada’s cap, but crowing is shameful in the eyes of certain reporters, “expert” sources, and columnists. They have unpacked, for the benefit of readers, the HDI formula and the validity of the data upon which it relies. Several news stories and newspaper columns provide about the same level of technical detail regarding the

HDI formula as I do in the preceding paragraphs. They also comment on the “political life” of this ranking in Canada. In particular, they chide the Prime Minister Chrétien for making so much of Canada’s score on the Human Development Index. For example, a column published in *Le Devoir* observes that because Prime Minister Chrétien relies on the UN report card as a bulwark against Quebec nationalism, Quebec separatists will give thanks when – not if – Canada falls to second place: «quand on descendra deuxième, ça va donner un sacré argument aux séparatistes» (Dion 1999). In 2001, Canada placed third, behind Norway and Australia.

The implicit reliance on the HDI in the *Toronto Star* editorial, “Our silence hurts native people,” to underscore that not all benefit from the fruits of “development” therefore represents punditry as usual in Canada. The invocation of the history of European colonization to explain why the average standard of living on “Indian Reserves” would rank “63<sup>rd</sup> in the world,” below many “developing countries,” is less common. Yet the spread of sweet blood does reflect Canada’s colonial history. The “personal stories” relayed in the “Lost People” series may be new to readers, noted the *Toronto Star*. “But the tale is as old as Canada.” (Toronto Star 2000) Far from bringing “development” to the “heathens” and the “hinterlands,” the editorial portrays European economic, geographic and demographic incursions as the root cause of many troubles currently facing Aboriginal peoples.

Furthermore, the comforts that readers presumably experience daily interlace with Aboriginal suffering, the editorial explained. “Through successive governments, we have contributed greatly to the problems faced by natives, and have failed repeatedly to do anything about them.” No wonder, says the editorial, “the Canadian Human Rights Commission calls the plight of native people a national tragedy” and “even a top official of a big conservative bank calls the situation of natives ‘Canada’s shame.’” The editorial concluded as follows:

It is time to remind Chrétien that the famous Red Book [a policy blueprint] which won him election in 1993 says that, ‘The place

of Aboriginal peoples in the growth and development of Canada is a litmus test of our beliefs in fairness, justice and equality of opportunity.’ (Toronto Star 2000)

In the end, this editorial translated Aboriginal suffering and struggles into “moments in which the future of the nation and its core institutions and values are ensured rather than shaken” (Povinelli 1998, 579).

The latter citation comes from an article about how Australians – through the courts, “fair and free” elections, mass media, and other institutions – have collectively paid heed to “the crisis of Indigenous citizenship,” only to dilute the issue, transforming it into a facet of contemporary, “multicultural” Australia. Oceans and continents separate the *Toronto Star*, Sandy Lake, and the Canadian Diabetes Strategy from the *Sydney Morning Herald*, Belyuen, the Kenbi land claim, and the Australian High Court’s judgement in *Mabo and Others vs. The State of Queensland*. Further, Australia’s history as first a British “penal colony,” then a “settler colony,” and then a “multicultural” country runs parallel to that of Canada’s at only certain junctures. Yet, in this case, the difference is in the details because Povinelli’s analysis holds.

In the best that the liberal democratic tradition can offer, the 30 April 2000 edition of the *Toronto Star* called upon voters to call their federal government to heel. The logic is formulaic. First, the *Toronto Star* feature conjures sympathy and outrage in readers by documenting the impact of diabetes on the residents of Sandy Lake and other Aboriginal people across Canada, “ball-parking” the price to pay in dollars and sentience, now and in the future. Then the companion editorial seeks to convert sympathy and outrage into shame. It shames readers, presumed to be non-Aboriginal, for tolerating inequalities between themselves and Aboriginal people across Canada; and it seeks to incite readers to heap shame on their politicians. Notably, the governing Liberals owe their three consecutive majorities (1993, 1997 and 2000) largely to Ontario voters, almost half of whom live in the Greater Toronto Area.

Distinguishing between non-Aboriginal and Aboriginal states-of-being in contemporary Canada evokes a shameful past, in which voters are judged

complicit, but also the prospect of edification. The editorial implies that dropping a ballot into a box, writing a letter to the Prime Minister of Canada, or “merely” ranking Aboriginal issues up there with “health care” whenever a pollster calls might appease the conscience and, one might hope, improve lives. Contemporary liberalism would seem to demand no less, nor offer more. Shame, shame, and only shame seemed up to the task at hand: governance by the majority, but without neglecting minorities, for the sake of the commonweal.

Through interviews granted by to journalists charged with conveying the conditions on “Indian Reserves” in Canada as an issue in need of better governance, residents of the Sandy Lake and Island Lake reserves have testified to suffering wrought by sweet blood and compounded by government policies, both past and present. Speaking through the medium of newsprint and television to voters across Canada and to politicians, they have underlined that the history – by no means complete – of colonialism roots the epidemic of sweet blood in their midst. Tutelage by the Canadian government has taken a toll on bodies and on minds, they have testified. They have to hope that enough people, the right people, will look and listen – really listen.

### **UNSWEETENING BLOOD THROUGH SEVEN GENERATIONS**

The “Registered Indians” who populate Sandy Lake and Island Lake are hardly alone in suffering from sweet blood and struggling with its manifold causes. Indeed, journalists and politicians alike have portrayed these communities as representative of a taxing present and of an alarming future. The symposium on “Theory, Reality, and Hope,” held as part of 1999 Canadian Diabetes Association Professional Conference and summarized earlier in this chapter, signalled that the Mohawk community of Kahnawake has been on the forefront of the battle. I will turn now to how these “Registered Indians,” together with personnel from McGill University and the Université de Montréal, are trying to arrest the flow of sweet blood. Their efforts illustrate how Canadian science, health, and “Indian Affairs” policies intersect with local governance and with the transnational movements of

people and information. This story has many origins and no end is in sight, but I will begin with a ringing telephone.

Mid-afternoon on 19 June 2000, the phone rang in my apartment in Montreal, which was strewn with boxes at the time. When I picked up the phone, I expected to speak French because I expected word on the missing-in-action moving truck. But the ensuing conversation took place in English: Alex McComber, who co-ordinates the Kahnawake Schools Diabetes Prevention Project (KSDPP), had called to instruct me on how to get to his home in Kahnawake, population 7100, 25 kilometres from downtown Montreal – about a fifteen-minute drive for the initiated. KSDPP’s Community Advisory Board would meet the next afternoon on his back lawn for a BBQ and a business meeting, and I was on their agenda.

Mr McComber’s instructions began with the Mercier Bridge. As I took notes, my thoughts leapt back to the summer of 1990. At the time, I was completing the final course for my bachelor’s degree in anthropology in Montréal and avidly following media reports about the “Oka crisis,” which made my blood boil. A 78-day armed stand-off between Mohawks and, first, the “SQ” (*Sûreté du Québec*, Quebec’s police force) and then the Canadian Armed Forces ensued when the municipality of Oka near Montreal set to expanding the local golf course on land claimed by the Kanehsatake Mohawks. In solidarity, barricades went up on the Mercier Bridge. “The Mercier” along with “the Jacques Cartier,” “the Champlain,” and “the Victoria” join the island-metropolis of Montreal to suburbs on the south shore of the majestic St Lawrence River. The “Kahnawake Indian Reserve,” as I remembered so well from the surfeit of media coverage about disrupted traffic flows in the summer of 1990, lies at the south end of the Mercier bridge (for first-hand Mohawk accounts of “the Oka Crisis,” see Obomsawin 1993; Obomsawin 1997; Obomsawin 1995; Obomsawin 2000).

In the wake of the Oka crisis, the Tory federal government of the day created a Royal Commission on Aboriginal Peoples. It released its final report in 1995 during a Liberal mandate. As noted in the previous chapter, this Royal

Commission's recommendations regarding health and health care presaged the creation under the Liberals of an Aboriginal Diabetes Initiative (under the umbrella of the Canadian Diabetes Strategy) and the Aboriginal People's Health Institute (within the Canadian Institutes for Health Research).

Over the course of my fieldwork, I frequently encountered the acronym, "OCA," pronounced just like "Oka," with all those two syllables evoke about Mohawk nationalism and, more generally, relationships between "ordinary Canadians," First Nations, and the federal government. Signaling the imperative of ownership of, access to and control over research data by First Nations, the OCA acronym clearly signals that colonialism involved, and depends still, on the codification and circulation of knowledge. Readers will recall that Dr Reading used and explained this acronym during his invited presentation at the 1999 Canadian Diabetes Association Professional Conference.

The next day, on and then coming off "the Mercier," I had to sneak a couple of peeks at the directions that I had scribbled on the back of a Hydro-Quebec envelope, highlighting another "Indian Affairs" sore spot in Quebec (see Salisbury 1986; Scott 1996). As I followed the signs for Kahnawake, I remembered navigating "the Mercier" a few months earlier, en route to skate on the frozen Rivière Châteauguay. On that occasion, the directions provided led *around* Kahnawake because, it was explained, Mohawks dislike outsiders cutting through their territory.

As signalled by this abbreviated account of my entry into Kahnawake, Indigenous nationalism suffuses the history and the plenum of everyday life in Kahnawake (see also Alfred 1995; Simpson 2000), fairly spilling over into Montreal, its suburbs, the whole of Canada, and beyond. This distinct nationalism has squarely confronted the Canadian and Quebec governments, as well as their predecessors, countless times since Jacques Cartier arrived by boat in 1535 and pronounced the rapids that prevented him from penetrating further inland, and what lay beyond them, "La Chine," in a moment of sublime Oriental ideation. The

name “Lachine” stuck to what is now a Montreal suburb. Kahnawake, in turn, means “by the rapids” in Mohawk.

Minutes after exiting “the Mercier,” I navigated a few twists and turns within Kahnawake and found myself in Mr McComber’s immediate neighbourhood. There were five or six cars lining the paved road on which his house sits, and a couple more parked on the other side. Slowly, carefully, I nosed the car through the opening and parked at the first opportunity – five or six houses down. I was glad to have found a parking spot in the shade of a tree; it was at least 30 degrees Celsius.

Approaching the house, I greeted a Mohawk woman in her late 20s who was seated on the front porch. I told her I was there for the meeting, but late for the party. She laughed at that, and directed me towards the backyard. About twenty people were gathered in a knot around Mr McComber, who stood between two flip-charts in the shade. He spotted me, and said Melanie Rock had arrived.

Dr Ann Macaulay, introduced in Chapter 3 (as a defender of routine screening in “high risk” populations), approached and invited me to take a seat – any seat – in the shade. Dr Macaulay is a physician who has served Kahnawake for over twenty years; she is also a professor of family medicine at McGill University. Just as I sat down, she asked if I had eaten. I shook my head and she said we could start with some fruit. She handed me a skewer with juicy pineapple, ripe cantaloupe, strawberries, and red grapes. A couple minutes later, by which time I had wolfed down the fruit kabob, she returned with a hamburger and salad on a paper plate. I smiled gratefully and piled into that. She also brought a package of written materials related to the agenda, which was printed in marker on one of the flip charts. Besides lunch, the first item, the agenda listed three Kahnawake-based diabetes research and prevention funding proposals, and then me. The meeting package included a page that I had composed for this audience, in which I described my research project, indicated that I would review KSDPP materials in the public domain, and sought permission to interview five or more of the people involved.

Before long, Mr McComber welcomed me to Kahnawake and noted that they had been planning for some time to have me address KSDPP's Community Advisory Board (CAB). Dr Macaulay added that my research has found that several government officials and researchers regard Kahnawake is a model initiative in diabetes prevention. I confirmed this. One CAB member suggested that I attend a then-upcoming Council meeting at which diabetes business would be discussed and asked about my "time lines." Another asked if I could present an introduction to medical anthropology for the community; I eventually did as part of the local hospital's continuing education program. Within minutes, questions ceased and Dr Macaulay asked if the group was prepared to make a decision; no one raised objections.

For hope and inspiration in the face of the sweet blood problem among Aboriginal and non-Aboriginal peoples alike, many minds leap and heads turn to Kahnawake. Several times during fieldwork, I was asked, "Have you been in touch with people out in Kahnawake?" because "they're doing such good work." The respect accorded KSDPP shines through articles published by international journals, recent speeches by politicians, and research funding announcements.

Several journal articles cite KSDPP research findings and testify to the benefits accrued from integrating research, broad dissemination of findings, and health promotion interventions in the community (Macaulay et al. 1997; Macaulay et al. 1998; Macaulay et al. 1999; Potvin et al. 1999, for example). The *1992 Clinical Practice Guidelines for the Treatment of Diabetes Mellitus in Canada* outlined the alarming increase of type 2 diabetes among Aboriginal peoples since 1940 and recommended "greater emphasis on prevention" with "involvement of the community," largely on the strength of the research and the beginnings of sustained community mobilization around diabetes in Kahnawake (Tan et al. 1992). Indeed, a Kahnawake Mohawk physician, Dr Louis Montour, sat on the committee charged with developing these guidelines. The updated *1998 Clinical Practice Guidelines for the Treatment of Diabetes Mellitus in Canada* rehearsed the impact of type 2 diabetes on this population and strongly endorsed

partnerships between health professionals, local political leaders and other community members, again based on the experience of Kahnawake, as well as of Sandy Lake:

The major focus of this strategy should be primary prevention, and a number of such initiatives are underway (e.g., in Kahnawake, Que., and Sandy Lake, Ont.). Programs aimed at schoolchildren and their parents are crucial for the prevention of diabetes in future generations.” (Meltzer et al. 1998)

It bears noting that the intervention strategy adopted in Sandy Lake explicitly drew upon the expertise developed in Kahnawake.

Canada’s Health Minister, Allan Rock, praised KSDPP and highlighted the contribution of federal funding to its accomplishments in launching the Canadian Diabetes Strategy in November 1999. “This highly successful project is run by the community for the community and includes a healthy breakfast program, cooking classes, food intervention and a variety of activities designed to help children become more active, thereby reducing their risk for the disease,” he said. Then he added, “We can already see that this program is working and we hope communities will take the lessons learned from this project and integrate them into school programs on other reserves.” (Rock 1999a)

These accomplishments have translated into funds for further research and for health promotion, and into more rhetoric emanating from federal circles that imbricates KSDPP with hope for the future. Upon announcing \$12.8-million in diabetes research funding through the Canadian Institutes for Health Research in Montreal during February 2001, Health Minister Rock’s Parliamentary Secretary, Yvon Charbonneau, highlighted a grant in excess of \$2.5-million to expand KSDPP and a Canada-wide network of projects modelled on KSDPP (Canadian Institutes of Health Research 2001).

KSDPP’s design expressly reflects the definition of health promotion as “the process enabling people to increase control over the determinants of their health” (World Health Organization 1986) and the ideals of respect and equality underpinning Mohawk nationalism (Delormier et al. 2001). These ideals extend to

descendants: all decisions should take into account the projected impact on the seven generations yet to come. This Mohawk principle of responsible governance is enshrined in a vision for a future articulated by Kahnawake Mohawks in 1995 that currently graces KSDPP's brochure:

All Kahnawakero:non [people of Kahnawake] are in excellent health. Diabetes no longer exists. All the children and adults eat healthily at all meals and are physically active daily. The children are actively supported by their parents and family who provide nutritious foods obtainable from family gardens, local food distributors and the natural environment. The school program, as well as community organizations, maintain programs and policy that reflect and reinforce healthy eating habits and daily physical activity. There are a variety of physical activities for all people offered at a wide range of recreational facilities in the community. All people accept the responsibility to cooperatively maintain a well community for the future Seven Generations.

Under the heading "Teiakonnekwenhsatsikhe:tare" (translated as "our blood is sweet"), KSDPP's brochure notes that type 2 diabetes has reached "epidemic proportions with rates up to 40% throughout Indigenous territories world-wide. Onkwehon:we (the original people) as young as ten are being diagnosed on Turtle Island" – meaning the territory labelled "Canada," the "United States of America" and "Mexico" on most maps.

In 2000, the Social Sciences and Humanities Research Council of Canada (SSHRC) awarded over \$150,000 to KSDPP for reflexive research on the "transformative processes of change" that gave rise to the project's remarkable history. When I first approached KSDPP researchers to discuss my interest in profiling this project, based on widespread recognition of its accomplishments, we marvelled at how their locally-grounded initiative and my use of "Canada" as a case study in the political economy of sweet blood had led us to similar questions.

The KSDPP researchers and I entered a collaborative arrangement that constructively reflects the salience of OCA (data ownership, access and control) concerns, and not least among Kahnawake Mohawks. Kahnawake refuses to participate in the Canadian census on nationalist grounds. Hence, the HDI results discussed earlier in this chapter suggesting that, on average, living conditions on “Indian Reserves” would rank 63<sup>rd</sup> in the world do *not* include data from Kahnawake Mohawks. Of this, the researchers with Indian and Northern Affairs Canada who calculated the HDIs for “Registered Indians” are very aware, and they are not alone. After an INAC researcher presented the most current HDI results for “Registered Indians” at a recent conference, an audience member said he thought participation in the census among Aboriginal people was really problematic. “But you’re telling me it’s all better now,” he said. Replied the INAC researcher, “No, not at all.” He cited Kahnawake as an example of a reserve that does not participate in the census, and he speculated that its HDI score would likely exceed the “on-reserve” average.

In light of OCA concerns (specifically, researchers extracting data from communities and then hoarding their troves), I amassed materials expressly placed in the public domain. Since the inception of KSDPP, the Community Advisory Board that granted my request to conduct research in Kahnawake has also approved the contents and dissemination of several scientific publications, many presentations at conferences, and a 25-minute video designed to spread knowledge about the efforts to unsweeten blood in Kahnawake.

Rather than conducting my own interviews (raising potential confidentiality concerns if I shared my interview data and schedule with KSDPP representatives, but OCA concerns if I did not), those interviewed by a KSDPP researcher about the history of the project could simply choose to participate in my study too. Besides their own consent form, KSDPP researchers administered on my behalf a consent form outlining the purpose of this project and indicating approval of my plans by KSDPP’s Community Advisory Board. Through this arrangement, I received four interview transcripts, but not the original interview

tapes. Twice, I travelled to Kahnawake to participate in the weekly face-to-face meetings between a Université de Montréal postdoctoral fellow, a Kahnawake Mohawk researcher (who has a master's degree in nutrition), and a research assistant (currently completing a master's degree in public health) involved in analyzing KSDPP's history. In addition to conducting tape-recorded interviews, these researchers are poring over minutes, project publications, and fieldnotes recording direct observations. We discussed, validated, and extended our respective conclusions about the history of KSDPP and its fit within transnational frames of reference, including Mohawk-Canada relations, during these meetings.

In the early 1980s, Dr Macaulay and her Mohawk counterpart, Dr Louis Montour, systematically reviewed charts from the local hospital and found high rates of diabetes and hypertension among Kahnawake Mohawks (Macaulay and Montour 1985). With an anthropologist, they extended their inquiries to the prevalence of diabetes-related “complications” and “risk factors” such as high body mass and smoking in the community. Their survey revealed that over 60% Kahnawake Mohawks with diabetes had macrovascular disease, more than six times the rate of macrovascular disease than among a sample of Kahnawake Mohawks without diabetes matched for age and gender (Macaulay, Montour, and Adelson 1988). At 48% among diabetics and 22% among the matched sample of non-diabetics, the rate of heart disease was the highest ever reported in a North American Aboriginal population. Further, 71% of the diabetics had hypertension, 86% were clinically obese, and 50% had retinopathy.

The decision to return these results to the community had galvanizing, far-reaching effects. In an editorial urging researchers to share their results with communities, published alongside their study on the prevalence of diabetes-related “complications” and “risk factors,” Drs Macaulay and Montour noted:

These results could be seen as very negative and depressing information to be returning to the community. We felt that it would help to present the results in the larger context of diabetes in general, the bigger picture into which we would then paint Kahnawake's specific findings.

(Macaulay and Montour 1988)

In light of these concerns, the researchers developed an hour-long presentation, repeated several times for various community groups. It covered the physiology of type 2 diabetes, its history among First Nations, studies of “complications” and “risk factors” in white populations, and the Kahnawake findings. They also disseminated their findings through the community radio station on an open-line show hosted by one of the study participants. “Immediately after this burst of information-sharing the number of people presenting for diabetes screening in our clinical practices increased and the dietician was swamped by self-referrals for dietary changes, weight loss and exercise advice,” Macaulay and Montour reported. The dissemination process also led to pressure for, and eventually the construction of, a recreation path to benefit the entire community. Especially significant for this story, reflecting the express wishes of the elders and the visible problem of obesity among primary schoolchildren, the dissemination of the results across the community fastened attention on the health of future generations (Macaulay and Montour 1988).

The road travelled so far by Kahnawake Mohawks and allied researchers towards a future untainted by sweet blood has not been without bumps, straitened circumstances, and hard scrabbling. Policies governing the allocation of federal funds for health research within the borders claimed by Canada have posed many obstacles.

Health Canada’s National Health Research Development Program (NHRDP) elected not to fund a proposal submitted in 1990 to support interventions designed to reduce the incidence of obesity and increase physical activity among Kahnawake children. One of those involved recalled:

NHRDP was having a major cutback in funding and so all of this work came to nothing...And so we resubmitted in 1992 when they had, NHRDP had a special call for proposals in diabetes in Aboriginal peoples and that was a result of a tremendous amount of lobbying in the country on NHRDP, that it was about time that they really did something to meet the need of Aboriginal people in the country. Because at that point the statistics were

starting to pour in about these high prevalence rates in different Aboriginal communities.

The original 1990 submission focused on intervention, but NHRDP regulations insisted that any funded interventions undergo evaluation to determine their effectiveness. Dr Louise Potvin, of the Université de Montréal, became involved “to translate people’s preoccupations into something acceptable for funding by NHRDP” through the design of an evaluation protocol. The 1992 submission to NHRDP received backing, and KSDPP began in earnest in 1994.

The project has undertaken a very wide variety of interventions that target elementary school children parents, teachers and the wider community. To judge their impact, the researchers have measured such things as body mass, physical activity, diet, and the degree of support for physical activity and for sound nutrition in the children’s social and physical environments. To situate Kahnawake schoolchildren’s bodily features in relation to a larger population on “Turtle Island,” the researchers have also compared KSDPP data with data matched for gender and age drawn from the National Health and Nutrition Examination Survey (NHANES) in the United States (Potvin et al. 1999, for example). As noted previously, Statistics Canada does not currently collect anthropomorphic measurements, nor blood sugar data, but will soon begin to do so in a survey modelled on NHANES. Whether Kahnawake Mohawks will participate in such an exercise will pivot on the handling of OCA concerns.

With Canada’s Health Minister singing KSDPP’s praises and claiming some credit for its success for his government upon launching the Canadian Diabetes Strategy in 1999, and with his Parliamentary Secretary spotlighting in 2001 an award of \$2.5-million to expand KSDPP and extend its accomplishments to other communities, I must underscore that KSDPP operated without any direct support from the Government of Canada from August 1997 until funds from the Canadian Diabetes Strategy’s Aboriginal Diabetes Initiative began to flow in 2000.

Pending further changes in health science policy that eventually led the CIHR, the NHRDP became a transition program in the late 1990s. Funded projects, however successful, became ineligible for further support. NHRDP funding for KSDPP terminated in August 1997:

And so we had a major financial crunch and we were in fact only able to get going after a lot of lobbying in the community, and in the end the Education Center, Community Services and Band Council each pledged \$30,000 to KSDPP, with the understanding that this money would be used to continue to pay the salaries of [Kahnawake Mohawks], community people, and the evaluation was dropped...

An application to the Medical Research Council of Canada came up dry: “MRC was not concerned at all with health services research, health promotion, population health, epidemiology.”

With support from private foundations, data collection resumed in 1998. The researchers found that the intensity of health promotion in the schools decreased and that the profile of health promotion across the community declined somewhat during “the bridge-funding year,” that is, the 1997-1998 school year. They believe that evaluation reinforces the overall benefits of health and how to secure these benefits among children *and* adults across the community (Potvin et al. under review). For example, having children run fitness tests at school for research purposes reminds teachers that regular physical activity is important. Also, KSDPP has regularly fed evaluation results back to community members through local mass media, but not in 1997-1998 because neither new results nor the human resources to write them up for community consumption were available.

Reflecting on KSDPP’s evolution, it seems that research conducted in and disseminated across Kahnawake in the 1980s catalyzed a community-based movement to avert the dangers of sweet blood. Converting and compiling knowledge that community members carried with them – embodied, perhaps, by a scar running down the middle of their own chest from heart surgery, an uncle

felled by stroke, a young niece growing so quickly into a very large body, a neighbour dependent on dialysis to survive – into “anonymous” statistics, comparing these statistics with other populations, and then circulating the findings across the community created a new priority, framed in terms of Mohawk tradition: unsweetening blood through to the seventh, yet unborn, generation. Funding for prevention and for further research cemented the commitment to unsweeten blood. KSDPP entered and won Canada-wide competitions governed by peer-review and other regulations, and it secured funds from local and private sources. At each step along the way, funders and their preoccupations helped shape activity (see also Bisset et al. 2001; Potvin et al. under review).

When Health Canada cut the purse strings, interventions (hope for the future, plus local employment in the here and now) took priority over the means (classifying, counting, anonymizing, comparing) through which sweet blood first became understood as a community-wide problem whose reach could extend far into the future. The arrested flow of NHRDP funds forced KSDPP to rely on monies from Kahnawake organizations funded by the Government of Canada to “permit” self-governance, as well as on charitable gifts.

The inception in 1999 of the Aboriginal Diabetes Initiative under the Canadian Diabetes Strategy renewed federal funding for diabetes prevention efforts in Kahnawake. And with the creation of the CIHR, a major restructuring of Canadian health science policy, the scope of the diabetes problem in Kahnawake and KSDPP’s accomplishments – particularly as recognized in several peer-reviewed articles – parlayed into substantial funding for further research, training, and the dissemination of knowledge designed to unsweeten blood. The “new money” will feed the “knowledge-based economy” threading through and well beyond Kahnawake; it will be used to train, employ, transport, and fasten together Kahnawake Mohawks in support of a common cause, along with people who hail from other places and who may well profess other nationalisms.

## MORALITY AND ITS DEVICES

The discussions about the impact of diabetes traced in this chapter tend to emphasize certain themes: similarities as well as differences between type 1 and type 2 diabetes; the estimated amount sweet blood currently flowing through the bodies of Aboriginal peoples, other “minorities,” and “the general population” in Canada compared to other countries; how sweet the blood of these populations is likely to be in the future; the measurement of human suffering wrought by diabetes, often through statistics and dollars; and the high value accorded longevity and, more generally, “quality of life.”

Diabetes researchers and organizations argue that the human and financial costs associated with diabetes warrant greater attention in Canada. They underline that sweet blood paves the way to pain – ranging from amputations to heart attacks, from “merely” pricking the surface of the skin several times per day to mental distress – and even “premature” death. Further, they argue that pharmaceutical products and other interventions may lessen the “human” costs of diabetes and, in some cases, reduce health care expenditures over the long term. Thus, they contend, people with diabetes should avail themselves of these “new and improved” treatments and other preventative measures, and governments should do their part by making these treatments accessible in the name of health, happiness and prudence.

The distribution of sweet blood complements *and* contests Canada’s privileged place in international report cards. In particular, the type 2 diabetes epidemic in many Aboriginal communities – where as recently as 50 years ago, sweet blood and its complications were virtually absent – underscores the persisting effects of colonization. Meanwhile, the increased proportion of the population who are “middle-aged” and “senior citizens,” and thus who are prone to type 2 diabetes, bespeaks progress. Yet the rising incidence of type 2 diabetes among “baby boomers”, young adults, adolescents, and even children suggests that “modernity” – in the form of the routine use of technologies such as televisions and cars, and the habitual consumption of “junk foods” – can induce

pathology and disability across “the general population.” In countries such as Canada, erstwhile luxuries have become so commonplace that people with lower incomes may find themselves at especially high risk for type 2 diabetes and its “complications.”

Type 1 diabetes, meanwhile, arguably demands greater attention, and it, too, indexes the vagaries of “development.” Children with the condition currently survive into adulthood, but they usually need two or more insulin injections per day, and they must intermittently test the sweetness of their blood. Since the disease tends to strike during childhood and adolescence, kidney failure, circulatory problems, and blindness often set in well before retirement age. Recent advances in transplant medicine have eliminated the need for insulin injections among a select few, fuelling the hope that more organ donations and more research could significantly extend and improve lives. Furthermore, “high-tech” research on and remedies for type 1 diabetes could bolster a “knowledge-based economy” in Canada, argue champions for more research into type 1 diabetes.

All told, sweet blood spells enormous expenditures on health care, now and in future. Such is the wealth of nations today. Money and what it can buy comprise central concerns in discussions about the impact of diabetes. In the Western philosophical tradition, the closer money comes to fixing the value of human beings, the more it disconcerts (Bloch and Parry 1989). Moral misgivings about weighing the worth of human life in monetary terms have, in fact, profoundly shaped methodologies in health economics. Instead of measuring the richness of life directly in dollars, health economists tend to use “impersonal” currencies such as HDIs (Porter 1992; Rock 2000c).

### *Misgivings about Money in the History of Social Science*

Marx famously objected to the egotistical calculation seemingly inherent in weighing all things, human labour included, in monetary terms. He argued that the amount of human labour congealed in an object should serve as the basis for

establishing its exchange value and that the intensity of need should drive distribution. In these regards, he allowed for the measurement of human worth vested in objects, expressed as units of “life time,” and for the gauging of human suffering (Marx 1954 {1887}, 46-48, 412-421). Indeed, his most famous interlocutor published an account that could qualify as the first ethnographic treatment of suffering (Engels 1973 {1892}).

Money’s apparent capacity to sever people from their handiwork and to cut through social bonds also disturbed Mauss. He argued that human beings became the “calculating machines” embodied in the individualistic, utilitarian, “cold reasoning of the business man, banker, or capitalist” only recently, and only in Western societies. Signs that “noble expenditure” was returning to Europe in the wake of the First World War, through taxation and public donation, gave him hope. In then-novel public policies such as employment and health insurance, Mauss saw “a return to law.”

Following Durkheim, his uncle and mentor, Mauss argued that consciousness imbues collectivities, such that, in many respects, members are of one mind. “Society,” from this perspective, comprises more than the sum of its individual members, and even at their most “natural,” human bodies enact and contest collective norms (Lock 1993a, 47). Mauss argued that, in non-Western societies, “social phenomenon are not discrete; each phenomenon contains all the threads of which the social fabric is composed” (Mauss 1967 {1925}, 1). Exchange, therefore, simultaneously and seamlessly carries spiritual, legal, moral, aesthetic, juridical, and economic import. Mauss confined this understanding of exchange to small-scale societies, but anthropologists such as Sahlins later perceived that, in “the West,” commodity exchange is so pervasive and so replete with symbolism that “the economy,” via money, interlaces with every other facet of everyday life (Sahlins 1976).

Among other ethnographic and historical examples, Mauss reinterpreted Malinowski’s analysis of *kula* exchange in Trobriand Islands, stressing that people embody and think in terms of collectively-held values. In summarizing

Malinowski's account of *kula* exchange, Mauss wrote, "The underlying motives are competition, rivalry, show, and a desire for greatness and wealth." (Mauss 1967 {1925}, 26, also 70-73) Thus, Mauss did not pretend that collective consciousness begets social equality, nor homogeneous experience. Malinowski, meanwhile, argued that individuals – not collectivities – do the thinking and feeling, albeit in a social context (Malinowski 1948 {1925}).

Malinowski and Mauss differed in their understanding of money, and in particular, whether *kula* valuables and Western money are akin, or merely analogous.

Malinowski likened *kula* valuables to crown jewels and, more generally, to precious metals or stones in "the West." In each of these cases, "conventionalised value...carries with it power, renown, and the pleasure of increasing both." Nevertheless, he objected to classifying *kula* valuables as a kind of currency (Malinowski 1922, 88, 351, 499). He maintained that currency, a term which he used interchangeably with money, exists only when people detach precious objects from all moral codes and social groups except those embodied by a state, which sanctions these objects as both units of exchange and as standards of value. Malinowski maintained that *kula* objects differ fundamentally from money because, as "cumulative possessions" (Malinowski 1922, 510), *kula* objects index the esteem of the individuals who hold them now and who held them in the past, whereas the value of money is impersonal.

Mauss insisted that the category, "currency," properly encompasses *kula* valuables and Western money. He observed that the more "subjective" currencies of exchange found historically and cross-culturally still "have the power to buy and this value can be computed." Since "the idea of number is present although the number is not fixed by a state authority," Mauss argued, other societies' precious objects "consequently deserve to be put at least in the same genus" as "money in our society" (Mauss 1967 {1925}, 94). According to Mauss, the practice of making precious objects into "money" – permanent, seemingly

universal measures of value – by severing worth from the association with known individuals and groups represents an historical development.

Marx, Mauss, and Malinowski, for all their differences, each decry the apparent capacity of Western money to separate people from kindred, and, in this way, to even bring new kinds of people into being. Each ascribes to money the *intrinsic* power to transform relationships and whole societies – perhaps the ultimate, dual instance of commodity fetishism *and* technological determinism (Bloch and Parry 1989, 3; Miller 1995; Pfaffenberger 1988). Pondering this conjuncture, I venture that money does exhibit special properties, and in this respect, I follow Simmel – but not blindly.

### *Money, Modernity and Its Contents*

Simmel – along with Marx, whose *Capital* he studied (Frisby 1978) – owned that money can erode social bonds; but he also maintained that money variously creates, loosens, and tightens diffuse social integration by fulfilling needs (albeit indirectly), generating desires, and reverberating bodily action. According to Simmel, the value ascribed to money indexes degrees of interdependence across populated geographies.

In these respects, Simmel’s stance is strikingly consonant with portrayals of *kula* exchange. Indeed, Simmel ascribes to money certain qualities that, according to Mauss, distinguish gifts from mere commercial transactions. Simmel wrote that “what money in its totality mediates is not the possession of objects, rather their exchange for one another” (Simmel 1978 {1900}, 211).

Unlike *kula* valuables, however, whose value fluctuates across face-to-face networks according to who possesses and possessed them, money engenders a form of spiritualization, through which “money increasingly becomes nothing but money” (Simmel 1978 {1900}, 441). Whereas what Bourdieu called “symbolic capital” marshals, activates, and ultimately counts in *kula*, money is the “factor X” that constrains and suffuses exchange in Simmel’s analysis of “the West” (Poggi 1993, 135). Even measures of prestige and taste – if not “individual

culture,” forthwith – can be acquired by virtue of banal monetary flows, Simmel observes sardonically (Simmel 1978 {1900}, 256-257, 432, 461, 448, for example). Although “sacred” *kula* exchanges interstice traffic in “profane” objects, *kula* valuables generally have more limited powers of substitutability than money (Malinowski 1922; Weiner 1976).

I have no quarrel with the notion that money serves as tool that people “operate not merely upon but also with,” congealing, transporting, and transforming value into all manner of things (Simmel 1978 {1900}, 209). And I concur thoroughly with Simmel’s observation that the quantification inherent to money permits sublime calculations, and thus minute comparisons, endowed with an ascetic appeal that *becomes* their very significance:

We know money, as such, more precisely than any other object; for since there is nothing to be known about it, there is nothing that it can hide from us. On account of its absolute lack of quality, it cannot, unlike the most insignificant object, keep surprises and disappointments up its sleeve. (Simmel 1978 {1900}, 244).

Yet, alighting upon the pleasure of transparent knowing afforded by money, Simmel embraces claims about its properties that do not find support in the present research project. These include: a growing intellectualization of experience at the expense of sentient subjectivity, a tendency to orient action by recursive reliance on cognitive rather than normative expectations, and the fostering of a detached, neutral mentality “appropriate to the selection and handling of a tool” (Poggi 1993, 139-145).

A tool it may be, but as such, similar to the poison oracle among the Azande (Evans-Pritchard 1976 {1937}), money conjures and apports emotion. Indeed, the veneration of “objectivity” associated with monetary value marks a “style of feeling” in a “moral economy” that straddles the boundary between scientific knowledge – including economics – and popular culture (after Daston 1995, cf.; Hacking 1992b). Contemporary forms of liberalism seek, variously, to unleash and channel emotion by fixing upon the future as a concrete realm to be

built through conscious decisions, made one at a time, decisions that often hinge upon the deployment of money. Money merges “totally with the function we assign it”(Simmel 1978 {1900}, 328), and so it can bespeak hope as readily as it can instil horror, or shame. Through research into the distribution of health inequalities, money can become a talisman, imbued with the power to give and take life (after Mauss 1967 {1925}, 93).

### *A Measure of Understanding*

To understand how sweet blood acquired greater social significance through monetization (of health care expenditures, for example), the line separating the patently “social” from the “material” blurs. Human bodies fairly jump out of their skins when rendered as a member of this population, or that expenditure column.

Transactions do not always follow directly from the conversion of life-blood into dollars, as when an epidemiologist predicts government expenditures for dialysis twenty years hence. That all the money in question is *not yet spent* (not yet possessed, not yet gone, not yet transformed into something else) may conjure emotion. As shown in this chapter, attention may fasten on the exercise of jurisdictional powers by “the state,” but also on such institutions as charitable foundations endowed with public trust (cf. Poggi 1993, 140, 150-152). Taxes and charitable donations – once parted from taxpayers or benefactors – take on “lives of their own.” Yet they may be expected to add value (health or satisfaction, for example) to the lives of the people parted from their money, thus remaining *parts of them* and constituting instances of giving-while-keeping (cf. Goddard 2000; Weiner 1992).

To make sense of how often, however awkwardly, I witnessed suffering concomitant with diabetes given *both* “a human face” and the face value of so many dollar bills, I have found it helpful to recall that money denotes and connotes value. Rhetorical appeals often invoke money precisely because the mere mention of the word levies emotional freight. And for this very reason,

money cannot show up randomly, nor casually, in crafting rhetoric about sweet blood – nor any other topic even remotely connected to the length and other “qualities” of human lives.

The conflation of money with suffering from sweet blood may strike some as a moral travesty, yet another example of “appropriation” (Das 1997; Kleinman and Kleinman 1997). Versed in such concerns, when structuring this chapter, I decided to lean heavily on examples of suffering placed deliberately in “the public domain” so as to rework only that already given out to a large audience. By focusing on “the public domain,” the imprecation of money became glaringly obvious, and curious. I am left believing that, in this day and age, suffering needs narratives studded with numbers (statistics, dollars) to become significant to strangers who remain distanced, who gauge the experience of others through television screens, newspapers, briefings, magazines, radios, and computers. To appreciate the scale and impact of phenomena, conversion into monetary terms helps. Money has real present value, and therefore, it can place the past and the future within ken. It is a measure of understanding.

## **8. Sweet Demographics: Trade in Glucometers, Recombinant DNA, Viagra, ‘The Pump,’ Splenda, Nicotine, and More**

At many junctures in this thesis, the estimated total economic impact of diabetes in Canada, usually pegged at \$9-billion annually, has surfaced as cause for broad public concern and as a way of conveying the cumulative impact of an often unheralded disease. This money does not disappear. The indirect costs of diabetes – lost productivity, for example – index wages and profits that never materialized. Money actually changes hands to cover the direct costs, generating sales and expenditures in equal measures, but for different parties. The calculation of both direct and indirect costs evokes an alternative present and a malleable future.

The present chapter will highlight processes through which the effects of diabetes may generate profit and, thereby, interest in the disease. A variety of private corporations currently construe people with sweet blood as a population replete with needs that may be met, at least in part, by exchanging dollars for goods and services. These needs tend to vary according to the “type” of diabetes and the presence of “complications,” but they may also vary by gender and age. The capacity to meet these needs also varies, notably by income and by insurance coverage.

Private businesses whose market includes people with diabetes are ultimately concerned with the extent to which broad trends find expression in specific locales. That is, they are ultimately concerned with *local* demography and epidemiology – *their* market, as opposed to “the market.” In this regard, “local” is an elastic term that can encompass the whole of North America, but it may also refer to a single village.

To call attention to how the profit motive currently combines with health concerns, this chapter will situate a particular line of business, drugstores, within

Canada's health care system. Pharmacies dot North American towns and cities, and they are also common in many other parts of the world. Yet these stores and the pharmacy profession itself – unlike physicians, nurses, and “non-Western” healers – have elided systematic attention among ethnographers, and social scientists more generally. The manufacture, prescription, and consumption of pharmaceutical products feature prominently in several recent ethnographic studies and review articles, but not their distribution (Clarke and Montini 1993; Nichter and Vuckovic 1994; van der Geest, Whyte, and Hardon 1996; Vuckovic and Nichter 1997; Vuckovic 2000).

Pharmacists have a legal monopoly over dispensing an array of pharmaceutical products across “the West,” including throughout Canada, but the “petty bourgeois image of retail pharmacy” has limited professionalization (Turner 1987, 144). In Canada and many other countries, drugstores sell pharmaceutical products, which carry a certain mystique, but also seemingly banal items such as toilet paper, greeting cards, and chewing gum. Presumably, this “general storekeeper” image has also deterred many sociologists and anthropologists from conducting ethnographic research among pharmacists and on the pharmacy business.

During the twentieth century, pharmacists compounded fewer and fewer medicines because an international pharmaceutical industry gained strength. Nevertheless, “the growing complexity of drug therapy, the growth of public concern about iatrogenic disorders, and the recognition that the public needs drug education and counselling has created new social roles for the pharmacist, especially in the area of hospital pharmacy” (Turner 1987, 144). In this chapter, I will examine how these new social roles have become articulated to retail drugstores.

The retail pharmacy business did not figure in my original research plans. Yet over the course of field research, drugstores became highly visible as places where a dizzying array of insurance plans, pharmaceutical products, medical devices, and supplies articulate with people whose blood is dangerously sweet.

These transactions interlace with the statistical “typing” of people. Since biomedical categories such as “type 1 diabetes” or “type 2 diabetes” establish certain people as in need of certain medications and supplies, these categories help structure the flow of money. In turn, the statistical analysis of sales, profits, and losses help structure merchandising, advertising, and promotions. As this chapter will show, via such statistics, sweet blood gained recognition in the 1990s as an important “business line” in the Canadian drugstore business. Through marketing and promotion campaigns, in turn, drugstore chains contributed to a renewed understanding of sweet blood as an urgent problem that can be redressed in the here and now.

### **PUTTING A DOLLAR VALUE ON HUMAN NEEDS**

Consumption and associated expenditures carry a moral valence when they are understood to augment or diminish health. Hence, the cost-effectiveness of a given clinical or public health intervention is often a prominent concern. For example, at the 1998 Canadian Diabetes Association Professional Conference, Dr Robert Turner, lead investigator for the landmark UKPDS type 2 diabetes clinical trial, presented the then-hot-off-the-press results and concluded by arguing that more aggressive treatment will improve lives and save dollars:

The costs of the increased therapies themselves – either for blood glucose or blood pressure – are directly recouped by reducing the time in hospital with the complications of diabetes. And so, not only will this [intensive blood glucose and blood pressure management] improve therapy through preventing complications, but it is actually good sense in either quality-of-life or cost-effectiveness [terms].

Dividing health “units” by dollars spent yields a cost-effectiveness ratio that quantifies a peculiar form of productivity: these ratios express how much “quality” in human lives can be gained (if not purchased outright) for a given amount of money.

A moral prohibition on expressing the value of human lives directly in dollars has fuelled reliance on a plethora of “end points” and “quality of life” instruments to measure and compare health status in populations (Epstein 1997; Koch 2000; Löwy 2000; Porter 1992; Rock 2000c for discussion). Human life, from this perspective, should be valued apart from money. Yet human lives are understood to vary in quality, and monetary flows have been associated with the length and overall quality of human lives. In anthropological terms, the practice of expressing “quality of life” in relation to dollars, as opposed to in dollars, signals the existence of distinct regimes of value that intersect, and that sometimes collapse into one another (after Bohannan 1959; Appadurai 1986; Kopytoff 1986).

Anthropologists have contrasted commodity with gift exchange in ways that reflect the “Western” tendency to separate monetary value from the value accorded human beings. They have frequently invoked the circulation and use of goods across “the West” in their writings to compare the society of ethnographic interest with social forms that readers presumably know intimately and intuitively. In doing so, anthropologists have often reproduced “Western” common sense when analyzing gift exchange in other societies, associating gifts with “good” (altruism, sociability, spontaneity, reciprocity) and commodities with “evil” (individualism, cunning, exploitation). More specifically, they have downplayed the role of gift exchange in cementing inequalities, and they have focused on resistance when examining the circulation and use of “Western” goods beyond “the West” (Appadurai 1986; Bloch and Parry 1989; Miller 1995).

In an influential synthesis of the commodity/gift distinction, Gregory postulates that gifts have an animate character that commodities usually lack because the latter tend to circulate outside the bounds of established personal relationships (see Figure 32). Social clout confers value on gifts and prefigures their circulation through face-to-face networks, such that the social origins of the things exchanged remain traceable, even after several removes. Therefore, anthropologists have fastened on “inalienability” as a cardinal feature of gifts, as

**Figure 32:**  
**“Commodities” versus “Gifts”**

<b>Commodities</b>	<b>Gifts</b>
Alienable	Inalienable
Independence	Dependence
Quantity (Price)	Quality (Rank)
Objects	Subjects

(Thomas 1991, 15, after Gregory 1982)

opposed to “alienable” commodities. Gregory, following Marx, argues that commodity exchange usually entails shallow and brittle relationships, which facilitate “alienation.” The conversion of heterogeneous physical forms into a single currency – that is, price formation – quantifies the value of commodities. In barter, from this perspective, the stuff of exchange is the price of the stuff.

Given a state of independence between the parties to exchange, prices express the value of commodities, but not the rank of people. Yet social rank may interweave with commodity consumption; the transformation of commodities to gifts provides a key case in point (Gregory 1982, 167-209; see also Miller 1995; Yang 2000). Moreover, in subjective terms, the remuneration of labour may encompass the valuation of persons. For Gregory, however, gift exchange is ultimately about conferring subjectivity; but commodity exchange – laid bare – involves a series of vapid transactions that, in the aggregate, set groups of people apart from one another.

Thomas argues that Gregory’s distillation of how commodities differ from gifts to exchange revolves around ideal types, which blur in practice: “Precisely because the theoretical contrast is developed with such clarity, the question arises of whether the postulated gift is anything other than the inversion of the commodity.” (Thomas 1991, 15) This question, in turn, supposes that anthropologists fully grasp the nature of commodification – at least in “the West.” Thomas observes that “commonsensical practical knowledge” dictates that, for example, “one does not go into a shop to establish or consolidate a social relationship.” (Thomas 1991, 8) This chapter finds otherwise. More specifically, this chapter shows how a network of shopkeepers – pharmacists –sought to establish and consolidate a social relationship with customers possessed of sweet blood.

Appadurai maintains that, due the emphasis on the commodity/gift distinction in the ethnographic literature, some processes that are common to all transactions have elided attention. He observes that all transactions, and even conceptualizing something as exchangeable, entail value-setting. He refuses to

define “the commodity,” and instead offers a definition of “commodity situations”: the situation in the social life of any thing in which its exchangeability – past, present, or future – for some other thing is a socially relevant feature (Appadurai 1986, 13). Things may move in and out of commodity situations, he argues, and thus once a commodity does not mean always a commodity (after Kopytoff 1986). Besides temporal shifts in whether or not a given thing seems exchangeable, Appadurai contends, some things seem more ripe for exchange than others in relation to a variety of reference points – be they symbolic, classificatory, and moral.

The gift/commodity distinction remains helpful analytically, not least because this distinction has local salience across “the West” and in many other enclaves as well. Yet, following Appadurai, I concur that the differences between commodity and gift exchange have often been exaggerated, such that the classification of transactions rather than the elucidation processes of valuation have commanded ethnographers’ attention. While Appadurai confines his analysis to the exchange of things as opposed to people (cf. Kopytoff 1986; Strathern 1992a), his insights helped me see that the statistical “typing” of people in biomedicine derives from value ascribed to human life that is, at once, categorical and qualified. Paradoxically, the inherent value assigned to human life leads to differentiating among people based on statistics that estimate the length and overall quality of their lives. Viewed this way, some people seem better off. In other words, the manner in which bodies perpetuate themselves until death, such that populations reproduce over time, gives rise to situations in which populations and individuals can be compared, and even ranked.

Given that biomedical practices affix qualified value on human life, and putting aside conventional understandings of commodities and gifts in light of Appadurai’s examination of the politics of need and desire, it is clear that the statistical “typing” of people construes human bodies as interchangeable things. Yet, and at the same time, each human body is unique, particularly from the perspective of the person contained therein (after Kopytoff 1986). This tension

between commonality and singularity defies resolution. Nevertheless, the notion that human beings are simultaneously fungible (as members of populations) and idiosyncratic (as individual persons) usually seems unremarkable. The evaluation of human lives and of things whose consumption affect the life course of human beings *sometimes* becomes highly charged. As shown in the previous chapter, giving population statistics “a human face” or the face value of a certain number of dollar bills can leverage diverse and powerful emotions (see also Rock 2000c; Kaufert 2000).

This chapter contributes to theory about how human bodies may become repositories of value under liberal capitalism by simply existing or, more specifically, by exhibiting perceived needs and the potential for meeting these needs. Notably, the *1998 Clinical Practice Guidelines for the Treatment of Diabetes in Canada* notes that people with diabetes may require insulin, devices to monitor their blood glucose levels throughout the day, and tailored advice to employ such technologies for maximum benefit.

To formulate this line of inquiry, I have found inspiration in Povinelli’s account of how Indigenous and non-Indigenous Australians evaluate hunting and gathering. She observes that some perennial questions in political economy – what type of action is productive? who decides? – fuel disagreements in contemporary Australia that, at their most stark, concern “what leisure produces” (Povinelli 1993, 169). Such conflicts surface in many venues, including legal opinions.

Similarly, I have found that professional knowledge about diabetes interlaces with the discernment of degrees of productivity arising from consumption, with particular concern for bodily action not bought and sold as waged labour. The human body’s routine conversion of food into glucose does not count as “labour,” but it underlies the capacity to labour. People with diabetes, whose cells cannot absorb glucose from the bloodstream, end up with dangerously sweet blood. Treatment can extend their capacity to labour and to live.

In step with global biomedical knowledge, the *1998 Clinical Practice Guidelines for the Treatment of Diabetes in Canada* focus on the potential for human control over the sweetness of blood. This document was written to help govern health professionals' paid labour, but also the "leisure" time of people with diabetes across Canada (Meltzer et al. 1998). For example, the authors exhort physicians to recommend that people with diabetes take prescribed medications as directed, undertake regular physical activity, carefully regulate their diet, and monitor their blood glucose levels (typically with one or more blood glucose tests per day). Aggressive treatment, which places demands on the patient's time and energy, has been shown to improve and save lives, the guidelines explain.

In addition to extending Povinelli's analysis of how bodily action other than waged labour undergoes evaluation under liberal capitalism, this chapter also follows cues that arising from Povinelli's data, cues suggesting that commodities differ in the degree to which they remain alienated (detached) from human beings. While she does not directly engage the definition of commodities, except for the valuation of "labour" and the possibility of "owning" land, Povinelli's portrait confounds the notion that commodities necessarily involve relations of independence and that they remain consigned to the status of "mere" objects. In particular, Povinelli's account calls into question the extent to which the exchange of commodities entails the detachment of people from people, as well as people from things. All commodities may not seem equally dispensable, such that the degree to which people perceive them to undergo alienation may vary. Notably, people all over the world increasingly buy the food necessary for their survival. In reproducing themselves, "buyers" and "sellers" of food items reproduce one another through vagaries in their degree of interdependence.

The residents of Belyuen, an Aboriginal community in Northern Australia, obtain most of their food from grocery stores, Povinelli reports. Store-bought groceries contain high quantities of refined sugar and flour, alcohol, and fats; nutritious "bush foods" collected "at leisure" complement and supplement these

purchases (Povinelli 1993, 178). The possibility of obtaining food elsewhere, either from the bush or from a competitor in a nearby town, mitigate against dependence on the local grocery store and provide an incentive for the local store to extend credit. “Belyuen Aborigines have a common market strategy of getting credit and delaying the payment of debts by making a store owner ‘sweet’ in much the same way that one makes a place sweet by visiting it and using it,” observes Povinelli. “The place, in this instance the store, gradually becomes familiar with the visitors and begins to give abundantly without requiring as much effort (here, money up front).” (Povinelli 1993, 194)

In the case study that I will present in this chapter, Shopper’s Drug Mart, a pharmacy chain, perceived “sweetness” in the diabetic population because people with diabetes must frequently obtain medications and supplies. They can obtain most of these items from a retail pharmacy only. The Shoppers Drug Mart chain has instituted measures designed to imprint professional concern for health onto a range of products and services. By highlighting the concern and knowledge embodied by the pharmacist, these stores actively try to induce people with diabetes and other regular customers to remain loyal, linger, and buy more.

### **CAPITALIZING ON SAFETY AND EFFICACY**

In trade shows, pharmacies, and diabetes classes, I came into contact with a perplexing array of technologies designed to control the sweetness of blood and mitigate related “health risks.” During formal interviews and through informal conversations, physicians told me that a recent surge in the availability of pharmaceuticals to control the sweetness of blood and such “complications” as cardiovascular disease have contributed significantly to growing recognition of diabetes as a serious health problem in Canada and elsewhere. The rising prevalence of type 2 diabetes, especially as the average age of the population increases, has made “the diabetes market” more attractive to corporations. In circular fashion, the attention paid to sweet blood and the availability of remedies reinforce one another.

***“There are Huge Human and Economic Costs”***

In 2000, at the outset of an interview with a physician-researcher, before seeking permission to turn on my tape recorder, I explained that I was trying to understand how diabetes had gained greater recognition over the last five years or so. Five years would be about right, my interview subject told me at that point. Midway through the interview, I asked why he thought so.

He indicated that he would probably answer “a lot broader” than I was anticipating, and then he rattled off a series of “factors” with ease bordering on delight. Each “factor” imbricated populations (present as well as future) with suffering and with dollars. By conjuring such diverse emotions as fear, pity, shame and “mere” greed, he implied, the valorization of long, healthy human lives has gained currency relative to sweet blood. Moreover, he asserted that the money has powered increased recognition for sweet blood. In particular, he took note of a growing array of pharmaceutical products prescribed to prevent and delay complications among diagnosed diabetics.

He noted that the average age of the population is increasing, driving up the prevalence of type 2 diabetes. Moreover, “the people who are ageing are baby-boomers and they're very interested in their health.” Next he underscored some powers embodied by Significant Ones:

You know, like Miss America [1999], for instance. She’s got type 1 diabetes.... And Newt Gingerach’s mother had it, and he brought it to Congress. So there are some high profile people out there. Mary Tyler Moore is a classic example.

Then he referred at length to the colossal impact of type 2 diabetes on “minority populations,” which together with the ageing of the population spell “*huge* human and economic costs.” He noted that the living conditions of Aboriginal people have become “a topic,” feeding “the desire of the Federal government to be seen to be doing something about Aboriginals in Canada.”

He also drew attention to an American survey that, unlike Canadian surveys conducted to date, includes weight, height, girth, and blood glucose

measures. This survey, known as NHANES (National Health and Nutrition Examination Study) yields credible estimates of the numbers of people with undiagnosed type 2 diabetes and the distribution of associated risk factors such as obesity across the United States. Researchers routinely extrapolate diabetes-related NHANES data to Canada, for rough figuring. Meanwhile, research with certain Aboriginal communities (he mentioned Kahnawake and Sandy Lake) in Canada and in the United States has employed standard measures, permitting comparisons with NHANES data.

He highlighted that, in addition to national snapshots such as NHANES, research on the extent to which sweet blood confers increased risk for cardiovascular disease has made diabetes seem more significant:

And then also at the same time there is growing recognition from the cardiologists and from the cardiovascular community that diabetes is a heart problem. It causes heart disease. And you know, the American Heart Association just recognized – you know officially – that diabetes is risk for heart disease. It's a bit ridiculous. But they actually just officially said this, even though it has been obvious from epidemiologic studies forever.... And that translates into a few things. One of them is the explicit inclusion of people with diabetes in the new trials. Until about 5 years ago, diabetes was excluded. That was one of the exclusion criteria for most large [cardiovascular] trials.

When cardiologists speak to an issue, he underscored, that involves “a huge other segment of the population.”

And the next one is the publication of clinical trials just on diabetes, and that's in '93 with DCCT [Diabetes Control and Complications Trial] and '98 with UKPDS [United Kingdom Prospective Diabetes Study]. Right? And those were both positive and generated a lot of interest in diabetes.

“So you have the demographics, and you have the evidence, and the evidence gets out into the media,” he said.

But what's fuelling this whole thing, underneath the thing, is the money. Because all of a sudden, pharmaceutical companies have had several drugs come to Phase 3 and then release in the last five years. That's why I said five years. Because every new diabetes drug that has been released in Canada and the United States has been released in the last 5 years. And before that, there were basically a couple of oral agents in Canada, one oral agent was safe, [plus] insulin.

This informant was not alone in highlighting how the pharmaceutical industry had helped raise the profile of sweet blood. Repeatedly, the physicians whom I interviewed contrasted the sure-fire efficacy of modern-day pharmaceuticals with the limited success that they had encountered in inducing "lifestyle" changes among their patients with type 2 diabetes. They also noted that problematic "lifestyles" express broader social trends over which they and their patients seemingly exert little control.

A family physician in private practice told me that he makes greater efforts to control cardiovascular "risk factors" such as lipid and glucose levels in the bloodstream than he did five or six years ago, largely because the pharmacopia has improved dramatically. Clinical practice guidelines are useful to him because they provide standards to which he and his patients can refer. He can explain that the patient's lipid or glucose levels exceed the recommended levels outlined in the guidelines, and then prescribe dietary changes and exercise. If (and usually when) diet and exercise fail to produce results, he will prescribe medication. The levels fall within the range recommended by the guidelines, the patient is happy, and he feels satisfied too.

Several physicians involved in formulating the *1998 Clinical Practice Guidelines for the Treatment of Diabetes in Canada* despaired at social trends that they anticipate will produce even more cases of diabetes in the near future. In other words, while the potential to delay and prevent "complications" of diabetes has been demonstrated in random clinical trials (especially the DCCT and the UKPDS), contemporary social and economic conditions, in concert with

embodied praxis, seem destined to increase the ranks of type 2 diabetics over the coming decades.

A physician who sat on the committee charged with developing the *1998 Clinical Practice Guidelines for the Treatment of Diabetes in Canada* observed that “we’re getting fatter and fatter.” Meanwhile, and he decried this trend, multiple levels of government in Canada have withdrawn resources for health promotion. As examples, he cited cut-backs in the number of in-school time devoted to physical education in his province of residence and the effective end of “Particip-Action,” a federal program dating back to the early 1970s that aimed to promote regular physical activity among children and adults. But “we now [know] what the risk factors [for type 2 diabetes] are, and we have strategies to do something. And unfortunately, it’s all drugs.” He lamented, “And we have no public programs to offer as an alternative. Education, lose weight, or be more active – normal people don’t do that.” He noted that publicly funded diabetes education programs across Canada have long waiting lists and that people “at risk” for type 2 diabetes do not qualify for their services. Waiting for an effective public policy that may never come is not really an option for the treating physician, he underlined. The patient could die in the meantime. To his mind, the treating physician should not simply hope that the patient will become “a born-again diabetic”: “It usually happens with their first heart attack or amputation, or it’s too late.” To follow the *1998 Clinical Practice Guidelines for the Treatment of Diabetes* to the letter, physicians will, in effect, “treat the hell out it.”

Another physician who helped draft the *1998 Clinical Practice Guidelines for the Treatment of Diabetes in Canada* laughed when I asked whether type 2 diabetes is truly preventable today:

Now? Now? I don’t know. [pause] I mean again, if you say ‘prevent,’ it depends if you mean some influence or totally prevent....There is some evidence suggesting that with diet and exercise – if people don’t gain weight, if they are able to lose weight – it might prevent the occurrence of the disease. Again, when you say ‘prevent,’ you have to use it with a time

relationship. Over three years, we might be able to prevent. Will they eventually get it anyway? That's uncertain. We have some studies going on now – that's not in the [1998] guidelines – to try to prevent, so we will see what comes out of that. I think we'll be able to decrease the frequency of diabetes.

He then underscored how patterns of consumption affect the sweetness of blood:

At the same time, we're battling lifestyle changes that are going way towards increasing the frequency – in a very dramatic way. Kids are more obese than ever, so now some kids have type 2 diabetes.

I was at Disneyworld with my family, and we were the only ones – At breakfast, in the hotel, there was a line-up for Coke at breakfast, sodas. We were about the only ones with milk. It's hard [to prevent obesity and type 2 diabetes] if you grow up with Coke, for breakfast.

Kids play Nintendo, etc. I have nothing against those games, but because of that, they do less sports, they are less active.

So anyways, I'm not sure if ever the population situation will improve, but that a think that in a given individual, we will be able to influence [outcomes].

This physician signals that the habitual consumption of packaged foods and packaged home entertainment may produce bodies prone to type 2 diabetes. From this perspective, commercial responses to, and stoking of, desires may yield bodies in need of remedy. The remedies on offer, for the most part, consist of a range of medical technologies. This same physician pointed out that he can “prescribe \$150 worth of [diabetes] medication, no problem.” In his province, public health insurance usually picks up the tab, or a private insurer will. But if he wants a patient to see a dietician every month, the response is, “No way.” Neither public nor private insurance will cover such frequent nutrition counselling. He invoked “human nature” to account for why so many people do not exercise as regularly or eat as well as they know they should – and he explicitly included himself in these ranks.

Trade in pharmaceuticals to control sweet blood and prevention-oriented interventions *both* commodify health and, by extension, actual human beings: both valorize life such that some ways of being seem superior to others (cf. Nichter and Nordstrom 1989; Vuckovic 2000). Yet in the practical circumstances that help shape lived experience, the valorization of human life is not absolute; it competes with other needs and desires. As highlighted by the existence of legions of smokers around the world, decades after research demonstrating that smoking reduces average life expectancy entered the public domain, people routinely and often knowingly do things that stand to shorten their lives.

### *Dollars, Pounds, and Prevention*

The role of private commerce in the political economy of sweet blood first hit home when I attended a workshop on insulin resistance sponsored by SmithKline Beecham, held in conjunction with the 1999 Canadian Diabetes Association Professional Conference.

Dr Lawrence Leiter chaired this workshop, which featured four presentations. Dr Diane Finegood reviewed methods to measure of insulin resistance; Dr Jean-Louis Chiasson outlined the role played by insulin resistance in the development of type 2 diabetes; Dr Amanda Adler discussed links between insulin resistance and “coronary events” using UKPDS data; and Dr Harold Lebovitz discussed a new class of drugs designed to combat insulin resistance already on the market in the United States, which piggy-back on the DNA-to-RNA transcription process.

The abstract for Dr Chiasson’s presentation drew attention to pertinent research and underlined that, at the time, none of the drugs on the market in Canada were effective against insulin resistance:

The only studies that we have suggesting that we can decrease insulin resistance and prevent [the] development of [type 2] diabetes are based on lifestyle changes – diet and exercise.... Both the Nurses’ Health Study and the University of Pennsylvania alumni study suggested that diet modification and

increased physical activity were effective in the prevention of type 2 diabetes. More recently, the Da Qing study showed that both diet and exercise could prevent the conversion of IGT [impaired glucose tolerance] to diabetes. Whether pharmacological treatment could be effective in the treatment of insulin resistance, and thus in the prevention of diabetes, remains to be answered. At the present time, none of the drugs available in Canada have been shown conclusively to have a direct effect on insulin resistance.

Periodically, Dr Leiter quizzed the audience about their knowledge about insulin resistance and its redress, as well as their approach to treating type 2 diabetes. Audience members could key in their answers to the multiple-choice questions using a device that resembled a 1970s calculator, but functioned more like a television remote control.

The final question generated considerable discussion. Dr Leiter asked the audience how often diet and exercise alone effectively optimize blood glucose levels among people with type 2 diabetes. At first, the question did not specify a time frame. Members of the panel said that it was important to specify the length of time after diagnosis, since changes instituted soon after diagnosis often fail to “stick.” The question was revised to ask how often diet and exercise alone optimize blood glucose levels among people with type 2 diabetes one year following diagnosis. Based on their clinical experience, 70% of the assembled indicated that diet and exercise alone are effective in about 10% of such cases. After these figures were tallied, a dietician suggested that different counselling methods yield divergent results.

Within a year, Health Canada approved SmithKline Beecham’s insulin resistance medication, known as Avandia®. The Canadian Diabetes Association’s magazine targeting adult diabetics indicated that more than two million prescriptions for the drug had already been written in the United States (*Diabetes Dialogue* 2000). It also identified Dr Lawrence Leiter as one of the investigators who tested Avandia® prior to its release. In November 2000, as noted in a

previous chapter, the Canadian Institutes of Health Research announced that it would join forces with four pharmaceutical companies (among them SmithKline Beecham) for a clinical trial designed to prevent type 2 diabetes. More specifically, this trial will investigate whether insulin resistance medications such as Avandia® or an ACE (angiotension-converting enzyme) inhibitor might prevent people with impaired glucose tolerance from developing type 2 diabetes (Canadian Institutes of Health Research 2000d).

Including insulin resistance medications, four classes of oral agents to control sweet blood among people with type 2 diabetes are currently sold in Canada under various trade names. Sulphonylureas stimulate pancreatic insulin release. In the 1970s, controversy plagued an early sulphonylurea, tolbutamide (Marks 1997). Biguanides, also known as metformin, mainly decrease glucose production in the liver, and they may also delay glucose absorption and enhance insulin-mediated glucose uptake. Alpha-glucoosidase inhibitors, also known as acarbose, slow down the absorption of starch and sucrose; this class of medication entered the Canadian market in 1996 (Canada. Health 1999c, 20; Meltzer et al. 1998, s15 for an overview of these four types of medications and contraindications).

The day after the insulin resistance workshop, the 1999 Canadian Diabetes Association Professional Conference began in earnest. Upon plunging into the exhibit hall, I was astounded by the breadth and depth of the reach of capitalism into diabetic bodies. As I moved from booth to booth, pausing frequently to jot observations, I noted the presence of several multinational companies and the wide range of their wares – from computerized blood glucose meters, to reprints of refereed articles, to low-calorie brownies baked with an artificial sweetener, Splenda®. Before long, promotional material strained the seams of the backpack that I received as part of the registration package.

Many of the conference sessions and “social events” named a pharmaceutical company as a sponsor, spotlighting once again their role in the political economy of sweet blood. A full house was on hand at seven o’clock in

the morning to hear Dr Bernard Zinman of the University of Toronto and Dr Loren Grossman, Vice President of Clinical Research for Eli Lilly Canada (and a former student of Dr Zinman) extol the virtues of a genetically-engineered insulin analogue. Bagels, cream cheese, fruit platters, and jugs of juice were on offer, buffet style.

Dr Zinman reminded the assembled that the DCCT, for which he was an investigator, suggested that post-meal glucose control is important, and that is why “Humalog needed to be developed.” Humalog® may be injected just five minutes before eating, unlike human insulin. Dr Zinman observed that many patients actually inject human insulin much closer to meals than the recommended forty-five minutes, and so in practice, Humalog® may prove even more efficacious than suggested by figures compiled by Eli Lilly.

The DCCT finding that tighter glucose control reduces the long-term likelihood of “complications,” as signalled by Dr Zinman’s remarks about Humalog®, have led to more intensive management of diabetes. Multiple (four or more) daily self-administered blood sugar tests and insulin injections are currently routine. Previously, patients usually injected insulin only twice per day, and many still follow this regimen.

Both Eli Lilly and competitor Novo Nordisk withdrew beef-pork insulin from the Canadian market in 1999 in light of the popularity of human insulin and insulin analogues (Canadian Diabetes Association 2000b). But some people with diabetes who used animal insulin for many years have experienced difficulty in switching to human insulin. The diabetes education class that I audited included one such person. She asked the endocrinologist who helped teach this class why the animal insulin option is no longer available. The endocrinologist noted that she was one of last ones to switch; she acknowledged this, saying that she tried about ten years ago but ran into problems. The endocrinologist explained that in the early 1980s, first Eli Lilly and then Novo Nordisk bioengineered human insulin. Eli Lilly put human genes for insulin in E.coli; Novo Nordisk put these genes in yeast. The main advantage, he said, is that these insulins are “identical to

what you [would] make.” He noted, “Now we’re in an age of designer insulins which have the advantages of unlimited supply and good quality control.” In addition, research conducted in the mid-1980s found that the injection of genetically-engineered human insulin leads to less antibody formation (Meltzer et al. 1998, s15).

Recombinant DNA products besides insulins and insulin analogues have entered the diabetes marketplace. From representatives in the exhibit hall, I learned that Janssen-Ortho has developed Regenex®, a gel that deploys “recombinant human platelet-derived growth factor,” which research found to be effective in people with diabetes (Wieman, Smiell, and Su 1998). People with diabetes frequently develop ulcers that, mainly due to poor circulation, refuse to heal and may even result in amputation. Kidney disease, another “complication” of diabetes, may also lead to reliance on a product bioengineered by Janssen-Ortho. Eprex® is a recombinant DNA product that substitutes for a hormone normally produced in the kidney, erythropoietin (EPO), which stimulates the production of red blood cells in the bone marrow. By increasing the number of red blood cells, Eprex® increases the amount of oxygen carried to the tissues. Reflecting its expense, one informant formerly administered a program providing Eprex® to Canadians with few means and poor insurance coverage for pharmaceuticals. Most patients who take Eprex® would otherwise require blood transfusions, a practice that gave rise to the expression, “the gift of life,” which currently infuses discussions about organ transfers and surrogacy (Sharp 2000, 303). Eprex®, in this light, represents a pricey commodity that can take the place of gifts.

From discussions with representatives in the exhibit hall, subsequent interviews, and a review of documents, it became apparent that the DCCT trial results stimulated the development of many products, among them, as mentioned above, an analogue to human insulin. In turn, the development of an insulin analogue helped made insulin pumps a practical alternative to daily injections.

Until recently, insulin pumps were about the size of a car battery. One of my interlocutors worked on an advertising campaign for insulin pumps in the late 1980s, a campaign that targeted hospitals because the technology of the day was not practical for use outside an institutional setting. Today, insulin pumps are not much larger than a pager. Similar to a pager, modern-day insulin pumps are usually worn on a belt or waistband. But unlike a pager, they must be worn at all times. Insulin continually enters the body through a tube based on a computerized calculation. Before eating, the person with diabetes increases the insulin dose to “cover” the meal. Dr Zinman and collaborators (among them Dr Chiasson) have found that insulin analogues used in combination with insulin lowers the average sweetness of blood among people with type 1 diabetes (Zinman et al. 1997). Currently, these pumps cost about \$5,000 each, plus supplies. To my knowledge, they are the only diabetes-specific device or product that pharmacists do not currently stock in Canada.

In a presentation on diabetes for medical students, a woman with type 1 diabetes outlined the advantages and disadvantages of the “the pump” over multiple injections. She told the medical students that “the pump” offers more flexibility than injections. Meal times need not be so regimented, which suits her busy and unpredictable schedule at work. She had recently attended a wedding, and was able to adjust her insulin under the table, rather than going to the bathroom and searching for a clean, private corner where she could inject. Referring to the fact that the pump must be worn at all times, she recalled, “The first day, my husband said, ‘I guess there’s three of us in bed.’”

In addition to prompting the development of insulin analogues and radical improvements to insulin pumps, the DCCT spurred a dramatic revolution in the technical capacity of people with diabetes to monitor the sweetness of their own blood.

Prior to the release of the DCCT findings, the available technology to people was very cumbersome. “You took a drop of blood, smeared it on a chemically-treated piece of paper, let it sit for a minute while the paper changed

colours, rinsed the blood off with water, and put the paper in the machine that read the colour.” (Rowan 1994) For the test to work, blood had to cover a fairly large area of the paper. And the water rinse could ruin the test. It was not uncommon for the person to try five times before obtaining a valid reading. “Multiply that by four readings a day, plus four to six insulin injections, and the person could tire of micromanaging the disease.” (Rowan 1994)

The new-generation blood glucose meters require much less blood. A disposable plastic test strip is inserted like a key into the device, which is smaller than an audiocassette and features a liquid crystal screen. Inserting the strip completes a circuit and turns on the device. Users typically prick a finger to draw blood, which the strip absorbs like a straw. A chemical reaction ensues. In the end, the device reads the amount of current released by an electrical charge. The sweeter the blood, the greater the electrical current. Less than a minute after drawing blood, the reading appears on the screen. Certain devices currently on the market allow users to store readings over time and download them into a spreadsheet program such as Excel©. At the time of writing, test strips cost about one dollar each. In other words, a person with diabetes might easily spend \$5 per day on testing strips alone, which would total over \$1,800 over the course of a year.

Impressed by the quality of the Eli Lilly breakfast presentation at the 1999 Canadian Diabetes Association Professional Conference, which focused on the insulin analogue Humalog©, I decided to attend the breakfast session the following day sponsored by Parke-Davis and Pfizer. It introduced new clinical practice guidelines for managing lipid disorders among people with diabetes. Imagine my surprise when, taking into account the theme, breakfast consisted of sausages and eggs. The fruit plate was picked clean when I arrived (at about 7:15 am) and the juice was already low.

Pfizer’s booth at the conference featured a Viagra© brochure targeting men with diabetes, which contains the following text:

The link between diabetes and erectile dysfunction is well documented. For example, diabetes is known to be one of the more common physical causes of erectile dysfunction. In fact, the two conditions are so closely associated that erectile dysfunction is one of the first visible signs of diabetes in 12% of all male patients.

Viagara© is but one pharmaceutical product prescribed to significant numbers of people diagnosed with diabetes, but that is not exclusively prescribed to people with sweet blood. For example, the UKPDS finding that tighter control over blood pressure among people with type 2 diabetes lowered complication rates bolsters the recommendation that physicians treat hypertension among people with diabetes more aggressively (United Kingdom Prospective Diabetes Study Group 1998).

As an array of pharmaceuticals target sweet blood itself and each associated “complication,” virtually every pharmaceutical company, every physician, and every pharmacist in Canada has a financial interest in diabetes. General practitioners and family practice specialists prescribed 86% of all diabetes-specific oral medications dispensed in Canada in 1997, and 63% of all insulin units dispensed (Canada. Health 1999c, 21). As these figures suggest, general practitioners and family medicine specialists treat the vast majority of people with diabetes, and almost all people with type 2 diabetes. From 1993 to 1997, the total number of diabetes-specific medications dispensed through retail pharmacies increased from about 370,000 units to at least 600,000 units (Canada. Health 1999c, 20). This increase captures prescriptions to unsweeten blood, but not to treat related “complications.”

### **HEALTHWATCH®: BRANDING CONSUMER CONCERN**

Faced with a plethora of clinical trials, pharmaceutical products, and medical devices related to diabetes, my main portal into the monetization of sweet blood became pharmacies, where Canadian consumers typically obtain these products. I decided to investigate how a group of drugstores fastened upon the

professional figure of the pharmacist and select diseases, among them diabetes, in marketing and promotion efforts. The sheer volume of products on the market today that promise to extend and ameliorate life has helped create a new niche for the retail pharmacist: assisting customers in optimizing their use of drugs and other health-related products. Ideally, the pharmacist sifts through information with, and on behalf of, the customer.

Shoppers Drug Mart is a chain of franchised drugstores. With outlets in every province of the country, it boasts more drugstores than any other chain in Canada. The chain operates under the Pharmaprix banner in Quebec in a bid to appeal to the province's francophone majority. According to independent market research, Shoppers Drug Mart and Pharmaprix pharmacists fill approximately 17% of all prescriptions and sell about 13% of all over-the-counter medications across Canada. A pharmacist, known as an "associate," owns and operates each store under a licence agreement. In return for a share of the profits that varies by store, the chain oversees advertising, promotion, store fixtures, and design. In recent years, many merchandising decisions and accounting tasks have been centralized as well. "The system combines entrepreneurial drive and close community ties with the benefits of national scale," according to a recent annual report (Bloom 1999).

I became aware of the company's focus on the pharmacist's role in managing diabetes at the 1999 Canadian Diabetes Association Professional Conference. Shoppers Drug Mart provided each registrant with a backpack that prominently displays the company name and its Healthwatch® logo. When I visited the Shoppers Drug Mart booth in the exhibit hall, the organization's efforts to promote the *1998 Clinical Practice Guidelines for the Treatment of Diabetes in Canada* caught my attention. While I had identified these guidelines as a key development, reflecting and increasing recognition for diabetes as a serious health concern, I had not anticipated that a pharmacy chain might serve as a significant player in the implementation phase. The representative also told me that the next "Diabetes Clinic Day" would highlight the UKPDS finding that tight blood

pressure control among people with type 2 diabetes reduces microvascular and macrovascular “complications.” I was versed in these results, but I had not anticipated that a pharmacy chain might play a significant role in transmitting them to people with diabetes. With further research, I came to appreciate that Shoppers Drug Mart has played a very significant role in raising awareness about diabetes and prospects for its control through in-store promotions such as “Diabetes Clinic Day” and through national advertising campaigns.

This case study is based on several sources, including: a formal interview with person who co-ordinated their diabetes education program since its inception, conducted at the Shoppers Drug Mart central office in Toronto; analysis of print materials about diabetes distributed to the public and to its pharmacists; a review of the Shoppers Drug Mart web site; direct observations in Shoppers Drug Mart stores and in competitor pharmacies located in three Canadian provinces (Quebec, Ontario, and Alberta); a review of over 300 newspaper articles; market research compiled by Statistics Canada and by private companies; the authorized biography of the founder of Shopper’s Drug Mart; print and internet sources documenting the history of the conglomerate that acquired Shoppers Drug Mart in 1978 and sold it in 2000; formal interviews and informal dialogues with physicians, other health professionals, and sales representatives for pharmaceuticals and other medical technologies.

### ***Health Insurance in Canada***

Before proceeding further, a few words on the structure of Canada’s health care system are in order. Commentators often mistake Canada’s health care system for a “socialized” system. In fact, publicly funded health insurance covers all physician and hospital services for all Canadians. The federal government transfers funds to the provinces to cover a portion of the costs entailed in delivering health care in clinics and in hospitals, provided that provincial health insurance plans embody five principles: public administration, comprehensiveness, universality, portability, and accessibility. Most physicians in

Canada run private businesses that bill the provincial government for services provided to patients. Their income depends on the number and type of services that they provide. Physicians who draw a set salary constitute a minority in Canada.

Provincial health insurance plans all cover products consumed and services rendered within hospitals, but these plans vary widely in the extent to which they cover pharmaceutical products and medical supplies prescribed for consumption off hospital grounds. Moreover, each province and each hospital sets its own “formulary,” the list of pharmaceuticals that physicians may prescribe. Many, but by no means all, Canadians receive coverage for a select range of pharmaceuticals, medical supplies, and such “ancillary” services as dentistry, massage therapy, or counselling through a private insurance plan, typically offered as part of an employee benefits package.

Insurance coverage for pharmaceuticals has repeatedly surfaced in charged debates about the future of Canada’s health care system, leaving a trail of newspaper articles highlighting speeches by politicians and the findings of several reports on the issue. For example, a recent *Globe and Mail* headline announced, “Six million lack proper drug plans, study finds” (Picard 2001c). The article reported that a 342-page document commissioned by the Canadian government found that 10% of the population have no prescription drug insurance at all, and another 10% are reimbursed 35 cents or less for every dollar spent on prescription drugs. Only 11% of the population can routinely obtain prescriptions without out-of-pocket costs. Disparities in insurance coverage tend to vary according to age, province of residence, occupational status, and health status. “Seniors are protected relatively well from high-risk drug expenses by government drug plans.” (Picard 2001c) Approximately 70% of those without insurance live in Canada’s most populous province, Ontario. “People with full reimbursement are found at both ends of the income spectrum: Those on social assistance and those with top-of-the-line employer-sponsored plans.” When combined drug costs reach

“catastrophic” levels, “93 per cent of Canadians can count on a combination of public and private plans to prevent serious financial hardship.” (Picard 2001c)

The next day, the Canadian Institute for Health Information released a separate report on the topic of pharmaceuticals, which garnered another *Globe and Mail* article (Picard 2001d). The amount spent on pharmaceuticals in Canada increased almost five-fold in fifteen years, the article’s lead paragraph reported. Canadians spent an estimated \$11.4 on prescription drugs in 2000, compared to \$2.6-billion in 1985. In addition, Canadians spent an additional \$3.3-billion in 2000 on such over-the-counter medications as cold and headache remedies; spending in 1985 on similar products totalled \$1.2-billion. Drugs currently account for almost 15% of all health care expenditures, surpassing total physician billings. Publicly funded programs covered only 31% of expenditures on prescription drugs, leaving consumers themselves or private insurers to pick up the other 69%. Canadians often assume, wrongly, that prescription drugs will be covered by public insurance, but “the reality is that there is a patchwork of private and public plans that provide wildly different coverage depending on age, income status, home province and medical condition” (Picard 2001d). In 1997, the federal Liberals presented a national “pharmacare” program as “a long-term national objective,” the article reminded readers. “But the perception that such a plan would be prohibitively expensive, combined with a lack of federal-provincial agreement, has moved pharmacare off the political agenda.” (Picard 2001d)

For people with diabetes and organizations such as the Canadian Diabetes Association, the cumulative, life-long financial impact of diabetes and the availability of insurance coverage to offset these costs are of deep concern. In an interview published in the Canadian Diabetes Association’s magazine targeting adults with diabetes, the then-newly-appointed public policy and government relations director, Debra Lynkowski, named government awareness of “the huge financial, emotional and social costs related to diabetes,” “full access to reasonable and adequate insurance coverage,” and the “drug review process and

pricing” as the three most pressing issues in her new portfolio (see *Diabetes Dialogue* 1999).

People with sweet blood are routinely deemed ineligible for life and mortgage insurance, while employer-sponsored health insurance plans *may* accept people with diabetes as clients. Employers may also choose not to include such diabetes-related items as syringes and supplies for monitoring blood glucose levels in their plans. One person raised his hand when I asked, during a formal interview, whether he knew anyone with diabetes who had been denied coverage under an employer-sponsored health insurance plan. He recounted that when a former employer changed insurers, the new company wanted to “do medicals” and representatives indicated that they would not insure him. But they were told that if they did not insure him, they would forego the contract.

Aside from out-of-pocket expenditures on pharmaceuticals to unsweetened blood and to treat related “complications,” many people with diabetes spend over \$1,500 on blood glucose test strips alone, year in and year out. Such costs do not necessarily count as “catastrophes” that trigger financial assistance on compassionate grounds. To underscore that insurance coverage for people with diabetes is a thing of shreds and patches, one informant told me that residents of oil-rich Alberta qualify for \$350 per year to cover supplies and medications, and an additional \$200 upon successful appeal; yet the Northwest Territories reimburses all such expenses, no matter the final tally.

The Canadian Diabetes Association currently offers travel and life insurance plan for members with diabetes. The travel insurance plan will cover 80% of expenses incurred outside Canada to treat diabetes or related “complications”; the life insurance plan is available to people with diabetes aged 20 to 75, contingent upon demonstrating the ability to control the sweetness of their blood. In interviews conducted for this project, I learned that the Canadian Diabetes Association marshalled findings from the DCCT and the UKPDS clinical trials to try to convince insurance companies to offer life insurance to people with diabetes. Their representatives argued that research has

shown that risk for complications such as cardiovascular disease varies according to degree of control over sweet blood, and thus, insurance companies should not categorically deny coverage to people with diabetes.

As this sketch of health insurance in Canada underscores, the financial resources available to people in Canada for managing their health vary dramatically as a function of earnings but also of insurance coverage. Governments and private organizations are both implicated in evaluations of the extent to which “the system” metes out fair treatment. One result of the current organization of health care is that the pharmacy has become a site where Canadians actively weigh the costs and benefits – financial and otherwise – of intensively monitoring and controlling the sweetness of their blood, among many other ominous signs and symptoms. Moreover, in pharmacies, the “opportunity” for intensive surveillance of one’s own health intermingles with other dimensions of “development,” reflected in a broad product mix: thermometers specially designed for babies, anti-wrinkle cream, soft drinks, hair dye, cameras, shaving cream, and lawn chairs, to name but a few.

### *Targeting Sweet Demographics*

In partnership with the Juvenile Diabetes Foundation, Shoppers Drug Mart has raised funds for diabetes research since the mid-1980s. A board member suggested that the company focus its corporate donations on this charity after his son developed type 1 diabetes. In the 1980s, black-tie fundraisers were the order of the day and regularly garnered mention in business publications. In 1988, for example, *The Financial Post* reported that a “gala evening” co-chaired by Shoppers Drug Mart CEO David Bloom raised almost \$1-million for the Juvenile Diabetes Foundation (Burgess 1988). In the 1990s, participatory fitness events came into vogue as fundraising vehicles. Shoppers Drug Mart became the lead sponsor of the Juvenile Diabetes Foundation of Canada’s annual “Walk for the Cure.” Besides walk-a-thons held annually in communities across Canada, Shoppers Drug Mart invites its customers to purchase a paper sneaker for \$1 and

inscribe their name on it; merchants then display these tokens of participation in their stores.

Upon being named one of Canada's top 200 chief executives in 1997, David Bloom said that he is proudest of "our involvement in the health-care community." He noted, for the record, "We are the largest corporate supporter of diabetes research in Canada." (cited in Financial Post 1997). The emphasis placed by Shoppers Drug Mart on the pharmacist as a health professional and the attention paid to diabetes in this regard evolved over the course of the 1990s. The company's current focus on health outcomes entwines with innovations in information technology, the franchise structure of the company, demographic trends, public policies, and pressure exerted by competitors.

In the 1990s, the American discount chain Wal-Mart entered and expanded across Canada, courtesy of the 1988 Canada-US Free Trade Agreement. Wal-Mart pharmacists currently dispense approximately 5% of all prescriptions in Canada. Its pharmacy department is not a "cash cow," but a "loss leader." Following Wal-Mart's entry into the Canadian market in the early 1990s, other department chains, big-box retail clubs (a novelty at the time), and grocery chains installed pharmacy departments; and, like Wal-Mart, they began using prescription and over-the-counter drugs as loss leaders. To drive down prices, these new players slashed dispensing fees, the fees levied by pharmacists on each prescription drug order that they process. A mail-order prescription business was also established in Canada during the early 1990s (Greenwood 1993). Presented with the possibility of obtaining the same prescription drugs for less from new players, consumers took increased notice of dispensing fees, as did third-party insurers, both public and private.

These dynamics played out in the Ontario government's adoption, in 1996, of a policy to contain pharmaceutical spending under its provincial health insurance plan and in the responses that this policy sparked from Wal-Mart and from Shoppers Drug Mart.

Since 15 July 1996, senior citizens and welfare recipients in Ontario pay \$2 for each prescription filled, whereas the provincial government used to absorb these dispensing fees in full. In response, Wal-Mart promised to absorb these charges. It also slashed its dispensing fees to \$4.11. Shoppers Drug Mart and other chain drug stores were charging about three times as much to process prescriptions (Brent 1996a). “Some retailers will elect to use pharmacy as a traffic builder and treat prescriptions as a commodity to sell more food or soft goods,” observed Shoppers’ CEO (cited in Brent 1996b).

But Mr Bloom’s company also prized health-related purchases for their capacity to draw customers into their stores, necessary to trigger all-important impulse buys. On the day that Ontario’s new policy took effect, Shoppers Drug Mart rolled out a discount program for Ontario seniors, but not welfare recipients. Dubbed the Healthwatch® Seniors Club, the program offers a 10% discount on its private-label stock, including vitamins, over-the-counter medications, and medical supplies (Brent 1996b).

In addition to campaigning to secure the business of people whose prescriptions public insurance plans cover by virtue of age or lack of financial means, Wal-Mart targeted employer-sponsored health insurance plans. In exchange for exclusivity, it offered “monitoring and counselling services to ensure maximum cost containment and efficient administration of prescription drug programs” (Brent 1996a). A consultant interviewed for the story noted: “It locks in a whole bunch of people that are affiliated with the partner, and it starts getting the message out that this is the lowest price.” He expressed surprise that Shoppers Drug Mart had not adopted this “clever strategy” (cited in Brent 1996a).

The new competition posed by the mail-order option, Wal-Mart, and other large-surface stores with pharmacy departments led Shoppers Drug Mart to re-examine its core customer base and business lines.

In 1994, market research among its pharmacists revealed that four conditions – diabetes, cardiovascular disease, asthma, and arthritis – generated more regular visits to Shoppers Drug Mart locations than any others did. Of these

four diseases, managers at Shoppers Drug Mart's central office decided to focus initially on diabetes, partly due to established links with the Juvenile Diabetes Foundation, but also due to profitability. Diabetes was identified as a significant "shopfront" category, meaning inventory besides prescription drugs, mainly due to the profit margins on equipment and supplies to monitor blood glucose levels. "Shopfront" sales had taken on renewed importance with new competitors offering lower dispensing fees on prescriptions and with the reclassification of many prescription drugs to OTC (over-the-counter) status as provincial governments sought to reduce health care costs. OTC drugs are not reimbursed under prescription drug plans, which can discourage their purchase (Bloom 1995).

In September 1994, Shoppers Drug Mart organized a trade show for its Toronto-area pharmacists, which featured equipment to monitor blood glucose levels. Recall that, in the wake of the DCCT results spotlighting the significance of intensive control over sweetness of blood, the technological capacity to self-monitor blood glucose greatly increased. This trade show provided Shoppers Drug Mart pharmacists with an opportunity to learn more about diabetes and to appreciate how the "newfangled" blood glucose monitors and supplies available for purchase in their stores, as well as the pharmaceuticals that they dispense, stand to affect health outcomes. They rated the experience highly. In 1995, a new corporate office position, the disease state manager, was created and a series of show-and-tell workshops modelled on the Toronto event took place across Canada.

In 1996, Shoppers Drug Mart intensified the focus on the pharmacist's role in diabetes management, with a view to positioning them as active and vital members of the diabetes health care team. In this capacity, pharmacists would rank among physicians, nurses and dieticians as advisors, facilitators, and advocates for self-care by people with diabetes. Shoppers' disease state manager prepared a resource manual to enhance pharmacists' understanding of diabetes and their role in its control. The company also printed logbooks for distribution to customers, which proved very popular. It turned out that although people with

diabetes are supposed to self-monitor the sweetness of their blood at regular intervals, they lacked a ready, steady supply of log books in which to record and track their routine blood glucose tests. This was a service that Shoppers Drug Mart could provide.

In 1998, the “Healthwatch® Diabetes Care Tool Kit” entered a new phase and the first annual Diabetes Clinic Day took place. By then, Shoppers Drug Mart had developed planning tools and held a “clinic day” to promote better use of asthma medications. “This was the pharmacist coming down from the upper echelon” and speaking directly to clients, the Shoppers Drug Mart disease state manager said when recalling this event in an interview with me. The “asthma experience” served as a prototype in designating a Canada-wide diabetes clinic day and developing a plan to help guide and reinforce diabetes counselling by Shoppers Drug Mart pharmacists (see Figure 33). The diabetes plan incorporates prompts to related information sheets on hypoglycemia, healthy eating, and blood glucose monitoring (see Figures 34 and 35). Each pharmacist also received a two-sided laminated card to assist them in matching “types” of customers with blood glucose monitors (see Figure 36). Here “types” of sweet blood join stock demographic variables, health insurance coverage, personality, computer skills, and the presence of certain physical limitations (such as reduced dexterity and vision impairment) as considerations in the purchase of equipment to monitor the sweetness of blood. In partnership with the Canadian Diabetes Association, Shoppers Drug Mart also developed and distributed a quiz, “Are you at risk?” to reach customers who had not been diagnosed with diabetes (see Figure 37).

Legislation governing health professionals prevents pharmacists from drawing blood. “What could we do without finger pricking that would be of value?” Shoppers Drug Mart central office staff asked. The emphasis on information in the Diabetes Clinic Day emerged in response. The “value-added” component would be knowledge about one’s own health, symbolized by a number that situated the individual in a large population. The number would help, and hopefully satisfy, individuals wanting to know, “How do I rate?”

Figure 33:

# Shoppers Drug Mart Diabetes Plan

## Diabetes Plan

Name \_\_\_\_\_ Date \_\_\_\_\_

Type 1     Type 2     Gestational

**Medications** *There are two types of diabetes medications: pills and insulin*

**Pills**  
The majority of people with Type 2 diabetes take oral medications. These pills are not insulin. There are three different types of diabetes pills. Your doctor will decide which is the best medication for you.

Oral medications you may take	When to take your pills	How it works	What to watch for
Sulfonylureas, eg. Gliburide <small>Name of your medication</small>	Take 15-20 minutes before meals	Helps your body produce more insulin	Hypoglycaemia <b>H</b>
Biguanides, eg. Metformin <small>Name of your medication</small>	Take with meals	Helps your body use your own insulin better	Metabolic taste, nausea, diarrhea
Complex Oligosaccharide, eg. Acarbose <small>Name of your medication</small>	Take with first bite of each main meal	Helps your digestive system process food more slowly so that your body's insulin is released more slowly	GI effects (eg. flatulence, bloating, diarrhea) especially during first two months of therapy but decreases with continued therapy

**Insulin**  
People with Type 1 diabetes require insulin. People with Type 2 diabetes may require insulin if diabetes pills no longer control blood glucose levels.

Type of insulin	Units/When to take	How it works	What to watch for
<input type="checkbox"/> Rapid-Acting, eg. Lispro	___ bkft. ___ lunch ___ dinner ___ bed	<ul style="list-style-type: none"> <li>Insulin works to lower blood glucose levels. Insulin allows the body to use food as energy.</li> <li>Your doctor will determine the best insulin type or combination of insulins for you to maintain balanced blood glucose levels.</li> <li>Different types of insulin work at different times.</li> </ul>	Watch for hypoglycaemia when taking any insulin
<input type="checkbox"/> Short-Acting, eg. Regular	___ bkft. ___ lunch ___ dinner ___ bed	<ul style="list-style-type: none"> <li>Insulin is injected in the fatty tissue just below the skin. Insulin can't be taken as a pill because stomach acids break it down before it works.</li> </ul>	
<input type="checkbox"/> Intermediate-Acting, eg. NPH or Lente	___ bkft. ___ lunch ___ dinner ___ bed		
<input type="checkbox"/> Long-Acting, eg. Ultralente	___ bkft. ___ lunch ___ dinner ___ bed		
<input type="checkbox"/> Pre-Mixed (Short and Intermediate Acting)	___ bkft. ___ lunch ___ dinner ___ bed		

Please see your HEALTHWATCH Blood Glucose Logbook for a section on recording your other prescription and non-prescription medications.

## Healthy eating

Healthy eating is essential to everyone, including you. In fact, healthy eating is as important to your diabetes care as the medication you take. You need to understand how the food you eat affects your blood glucose control. A registered dietitian can suggest the best foods for you.

Have you ever attended a diabetes education centre?  Yes  No

The telephone number of your closest diabetes education centre is \_\_\_\_\_

## Active living

Active living is important to your health and well-being. Active living is as important to your diabetes care as the medication you take and the food you eat. It can mean walking, cycling, dancing or snowboarding. Choose activities you enjoy. Be sure to discuss any new activity with your doctor or diabetes nurse educator.

## Blood glucose monitoring

Blood glucose monitoring helps you understand the balance between medications, healthy eating and active living. Everyone with diabetes should self-test blood glucose levels regularly.

Do you self-test blood glucose levels?  Yes  No

**Blood Glucose Monitor Notes**  
Name of monitor/strips currently used:  
• \_\_\_\_\_  
• \_\_\_\_\_

**When shall I test?**  
Breakfast  before  
 1-2 hours after  
Lunch  before  
 1-2 hours after  
Dinner  before  
 1-2 hours after  
Bedtime  before

Your HEALTHWATCH Pharmacist is able to determine the most appropriate monitor for your needs. Please ask for a personalized HEALTHWATCH blood glucose monitor assessment.

The recommended monitor(s) for me are:  
• \_\_\_\_\_  
• \_\_\_\_\_

Your HEALTHWATCH Blood Glucose Logbook will make recording easier.

Name of HEALTHWATCH Pharmacist: \_\_\_\_\_ Phone Number: \_\_\_\_\_

**HEALTHWATCH**  
A SHIPPERS DRUG MART  
Slogan  
**MEDISENSE**

Figure 34:

## Shoppers Drug Mart Diabetes Plan (continued)

### Treatment of Hypoglycaemia



People with diabetes, who are taking insulin\* or diabetes pills, may occasionally experience low blood glucose levels (hypoglycaemia). People who manage their diabetes with exercise and meal planning only are not at risk for hypoglycaemia. Hypoglycaemia is any blood glucose level that is lower than your acceptable range. It is important to know how to prevent hypoglycaemia, and how to recognize and treat it.

You should always carry with you a fast-acting sugar to treat hypoglycaemia such as glucose tablets or glucose gel.

#### Hypoglycaemia is caused by:

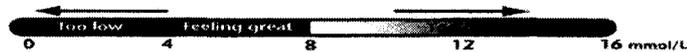
- not enough food, or delayed food;
- too much insulin or diabetes pills; or
- extra activity or exercise.

Take note of how often you are experiencing low blood glucose levels. If they are happening frequently — two or three times per week — you may need your doctor to adjust your diabetes medication or management plan.

\*Note: Hypoglycemia unawareness sometimes occurs in people with Type 1 diabetes. That means common hypoglycemic symptoms are absent, even though blood glucose levels are too low. Check blood glucose levels more frequently, especially when operating a motorized vehicle. Carry Glucagon & ensure people close to you know how to use Glucagon.

#### When you have low blood glucose you may have some of the following signs:

- |          |             |                  |                        |
|----------|-------------|------------------|------------------------|
| - shaky  | - hungry    | - confused       | - blurred vision       |
| - dizzy  | - emotional | - headache       | - cannot concentrate   |
| - tired  | - nervous   | - nausea         | - increased heart rate |
| - sweaty | - irritable | - slurred speech |                        |



#### What to do:

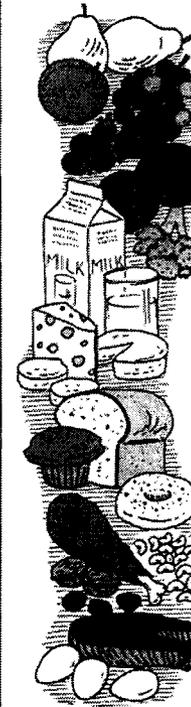
1. As soon as you know you are having a hypoglycaemic reaction — if you recognized your symptoms or if your blood glucose level is less than 4.0 mmol/L — take a fast-acting sugar. Always treat the symptoms, even if you are unable to monitor your blood glucose level.
2. If you have low blood glucose levels, take one of the following:
  - 1/2 cup of juice
  - 2 sugar cubes
  - 3 glucose tablets\*\*
  - 1/3 cup of regular pop
  - 6 jelly beans
  - glucose gel\*\*
3. Wait 10 to 15 minutes. Repeat the treatment if your symptoms persist or if your blood glucose level is still below 4.0 mmol/L. If your next meal is more than an hour away, eat a starch & protein choice (e.g. cheese & crackers) to ensure the blood glucose level will stay up until the next meal or snack.

\*\* Note: These are the only recommended treatments of hypoglycaemia for patients taking acarbose in combination with sulfonylurea or insulin.

This is a general guideline for the treatment of hypoglycaemia. Discuss treatment of hypoglycaemia with your diabetes care team to plan individualized diabetes care.



### Healthy Eating and Diabetes



#### What should I eat when I have diabetes?

Eat well-balanced meals with a variety of foods from all four food groups. This is a healthy way of eating, whether or not you have diabetes. There is no need to buy expensive, special foods, such as those marketed as "dietetic".

#### What is healthy eating?

Healthy eating means:

- having three meals each day, including breakfast;
- having three of the four food groups at each meal:
  - starch foods, fruits and vegetables, protein food and milk;
- having portion sizes that help you reach or maintain a healthy body weight; and
- having meals four to six hours apart.

#### Should I follow a meal plan?

It depends. Everyone has specific needs. A meal plan is based on the healthy eating principles mentioned above. A dietitian will work with you to design a meal plan that will suit your needs and balance the food you eat with the insulin you have in your body.

#### Do I need to think about fat content in foods?

Yes. Eating less fat will help you maintain a healthy heart. Eating less fat may also result in some weight loss, which will help your body to use insulin better. Consult a dietitian to discuss fat content in foods and ways to lower it.

#### Can I have sugar?

Yes. Studies have shown that sugar can be a part of a healthy meal plan for people with diabetes. First, you need to be sure you are eating healthy meals. Then, foods containing added sugar are incorporated into your meal plan. Be sure to discuss added sugar with a dietitian.

#### Can I have artificial sweeteners?

Yes. Artificial sweeteners are approved for use by people with diabetes, and can be used in moderation. Sugar-free does not mean calorie-free. Foods that are artificially sweetened may contain calories that will affect your blood glucose levels.

#### How do I locate a dietitian?

Contact your local Diabetes Education Centre.



Figure 35:

## Shoppers Drug Mart Diabetes Plan (continued)

### Blood Glucose Monitoring



**Who should monitor blood glucose levels?**  
Anyone who has diabetes (Type 1, Type 2, or gestational).

**Why is it important to know your blood glucose levels?**

The information from these simple tests gives you the ability to make independent and timely decisions about managing your diabetes. Monitoring can help your diabetes care team (doctor, nurse, dietitian or pharmacist) to evaluate patterns so they can help you make changes affecting your food intake, activity levels and, for those who take it, insulin dosage.

**Should my blood glucose level be?**

Four to eight — feeling great! A general target range is 4 to 8 mmol/L before meals.

**When should I monitor my blood glucose level before or after meals?**

Generally, people with Type 1 diabetes test blood glucose levels prior to meals & bed. This indicates fasting blood glucose levels. People with Type 2 diabetes generally test blood glucose levels 2 hours after meals. This indicates how well therapy is

working to bring down post meal blood glucose.

**How often do I monitor?**

Determine the frequency and timing of blood glucose monitoring with your diabetes care team. Some people will monitor as often as six to eight times each day, while others may monitor once a week. Other people, working to bring their diabetes under control and assess the patterns of their blood glucose levels, usually monitor four times a day — before each meal and at bedtime. Random tests are used to detect low blood glucose levels, and additional tests can be done during illness and when adjusting insulin or food or exercise.

**Accuracy Tip**

Immediately following a lab blood test, perform a blood test using your own blood glucose monitor. Circle the result in your HEALTHWATCH® Blood Glucose Logbook. When you get the lab results from your doctor, compare it to the results circled in your Logbook. Your monitor should read within 15% of your lab results. This means your monitor is accurate. If the results are off by more than 15% discuss with your HEALTHWATCH Pharmacist.



Use your complimentary HEALTHWATCH Blood Glucose Logbook to keep track of your blood glucose levels. Discuss your target blood glucose levels and results with your diabetes care team.

#### Obtaining a good blood sample

Obtaining a good size drop of blood can be one of the biggest challenges of blood glucose monitoring. It is important to get a good size blood drop to obtain an accurate reading.

This information will help you obtain a good size drop of blood so that you do not have to poke your finger more than once or waste test strips when monitoring your blood glucose level.

**Why do I have trouble getting a good blood sample?**

Some people have a hard time getting enough blood for glucose monitoring. As we get older, the circulation in our hands changes. This is especially true if you have cold or calloused hands.

See the other side for step-by-step instructions on getting a good blood sample.

#### What should I do to get a good blood sample?



**Step 1:**  
Wash and dry hands. Wash your hand below your heart to increase its blood flow. If your hands are cold, try washing with warm water.



**Step 2:**  
Prick your finger on the side, not too close to the nail bed and not too far down toward the knuckle. Avoid pricking the pads of the fingertips because these are the most sensitive part of the fingers.



**Step 3:**  
Count to 10 and don't touch your finger. This allows the blood to flow more easily. If you squeeze the finger too soon, it's like applying pressure on a cut to stop bleeding. The pressure stops the blood from flowing.



**Step 4:**  
Squeeze the inside of your finger toward the fingertip. Then, let go of the finger. Allow the blood to return to your finger, and squeeze it again. You should only need to squeeze your finger two or three times to obtain a large enough drop of blood.

The goal is to prick your finger only once and use only one test strip for each blood glucose test.

If these tricks don't work you may need to consider changing lancing devices. Some lancing devices prick your finger deeper than others. You can select the depth of puncture on some lancing devices or select a cap that pricks your finger more deeply. Ask your HEALTHWATCH Pharmacist to show you various lancing devices so you can select the one that is best for you.

#### How to use your blood glucose monitor

Once you have selected a blood glucose monitor, you will need to learn how to use it properly. The accuracy of your readings is often determined by your ability to use your monitor correctly.

Your HEALTHWATCH Pharmacist will show you how to use your blood glucose monitor. This checklist is meant to compliment the instruction manual included with your monitor.

1. Gather supplies — monitor, test strip, lancet, lancing device and tissue.
2. Wash and dry hands.
3. Ensure the calibration number or the code on the monitor and test strips match.
4. Remove test strip from container or packaging. Replace the lid of the container immediately.
5. Insert strip.
6. Turn on monitor. (Some monitors turn on automatically when the strip is inserted).
7. To obtain a large drop of blood, prick finger on the side, avoiding finger pads.
8. Apply drop of blood to test strip. Place tissue on prick.
9. Watch for blood glucose result on display.
10. Record the result in your HEALTHWATCH Blood Glucose Logbook.
11. Remove the strip and discard it. Turn off the monitor.
12. Discard lancet in a covered, puncture-resistant container, or sharps disposal container.



MEDISENSE

Figure 36:

## Shoppers Drug Mart Blood Glucose Monitor Selection Tool

### Monitor Assessment & Selection Tool

FOR HEALTHCARE PROVIDERS USE ONLY

**How to use:**

- Review the 1st column. It lists common patient characteristics.
- Review the 2nd column. It lists the monitor characteristics.
- Review the 3rd column. It lists blood glucose monitors most suited to columns #1 and #2.

Patient Characteristics	Monitor Characteristics	Suitable Monitor
<b>Health information focused</b>	Accuracy	Precision QID Glucometer Elite One Touch Basic SureStep Accusoft Advantage
<b>Visually challenged</b>	<ul style="list-style-type: none"> <li>• Large numbers</li> <li>• Requires small drop of blood</li> <li>• Easy to clean</li> <li>• Easy to see where drop of blood is to be placed</li> </ul>	SureStep One Touch Basic (audio component available) Glucometer Dex*
<b>Reduced dexterity</b>	<ul style="list-style-type: none"> <li>• Easy blood application</li> <li>• Strips in canister</li> </ul>	One Touch Basic SureStep Accusoft Advantage
<b>Insured</b>	Monitor covered by plan	Check with individual insurance providers or government plans.
<b>Cost focused</b>	Lowest cost *Contact provincial CDA office to inquire regarding assistance	Precision QID One Touch Basic Accusoft Advantage
<b>Convenience seeker</b>	<ul style="list-style-type: none"> <li>• Autocalibration</li> <li>• Preloaded test strips</li> </ul>	Glucometer Dex*
	<ul style="list-style-type: none"> <li>• Uses smallest blood sample</li> <li>• No cleaning required</li> </ul>	Glucometer Elite FastTake*
<b>Simple needs</b>	<ul style="list-style-type: none"> <li>• Easy to read</li> <li>• Simple to use</li> </ul>	Precision QID Glucometer Elite One Touch Basic Accusoft Advantage
<b>Computer literate</b>	Data extension available from manufacturer	Precision QID FastTake*

Continued over...

### Monitor Assessment & Selection Tool

FOR HEALTHCARE PROVIDERS USE ONLY

Patient Characteristics	Monitor Characteristics	Suitable Monitor
<b>Type 1 (child)</b>	Memory feature important for parents (+100 test memory)	Precision QID Glucometer Dex* Accusoft Advantage
<b>Newly diagnosed (Type 2) Apprehensive about cost and blood glucose testing</b>	<ul style="list-style-type: none"> <li>• Simple to use</li> <li>• Lowest cost</li> </ul>	See cost focused column
<b>Language</b>	French  Language prompts: French, Spanish, German, Dutch, Italian, Portuguese, Swedish, Danish, Norwegian, Finnish, Greek, Turkish, Hungarian, Czech, Polish, Russian, Japanese	All  One Touch Basic

Monitors	UPC Code
LifeScan One Touch Basic Glucose Kit	3 5388510545 3
LifeScan SureStep Blood Glucose System	3 5388565801 0
Medisense Precision QID Kit	4 98758497463 6
BMC Accusoft Advantage Kit	0 6456221216 5
Bayer Elite XL Glucometer Deluxe Kit	0 5650003903 3
Optional Monitors	UPC Code
LifeScan FastTake	3 5388545701 9
Bayer Glucometer Dex	0 5650003953 8
Non Monitor Option	UPC Code
LifeScan SmartStrip	3 5388501705 3



**SHOPPERS DRUG MART**

**Figure 37:**  
**Are you at risk?**

			
<h2>Are You At Risk?</h2>			
<p>Your HEALTHWATCH® Pharmacist has provided this simple test, prepared in co-operation with Canadian Diabetes Association, to help determine if you are at risk of developing diabetes. Why? Earlier diagnosis means earlier treatment to reduce the risk of complications.</p>			
<p>Circle the answers that apply to you</p>			
Would you say that you are overweight? (for most people of average height, this may be about 25-35 lbs or 11-16 kg over your healthy weight range)	yes	no	2
Do you have a parent, brother or sister with diabetes?	yes	no	2
Are you over age 45?	yes	no	1
Are you a woman who has delivered a baby over 9 lbs (4 kg)?	yes	no	2
Are you of Aboriginal, Metis or Inuit descent?*	yes	no	1
Are you of Latin American or African descent?*	yes	no	1
Do you experience excessive thirst?	yes	no	3
Do you have to urinate frequently, even at night?	yes	no	3
Do you experience excessive fatigue?	yes	no	1
Are you experiencing blurred vision?	yes	no	2
<p>Add up points for each "yes" answer and total the score.</p>			<input type="text"/>
<p><b>Are you at risk?</b></p> <p><b>Four or less points</b> Low risk. But you should know the symptoms and be watchful, especially if you're over 45, overweight, or belong to one of the greater risk groups.*</p> <p><b>Five or more points</b> You may be at a greater risk of developing diabetes. You may even have diabetes and not know you have it. Discuss the results of this quiz with your doctor at your earliest convenience. Only a medical doctor can determine if you have diabetes.</p>			
<p><b>Whether you have diabetes or are trying to prevent it, you should take the same course of action:</b></p> <ul style="list-style-type: none"> <li>• Maintain a healthy body weight;</li> <li>• Exercise regularly – 20 minutes, 3 times a week;</li> <li>• Eat a well-balanced, low-fat diet;</li> <li>• Don't smoke;</li> <li>• Learn to reduce or manage stress in your life; and</li> <li>• See your doctor regularly.</li> </ul>			

The Shoppers Drug Mart central office has sought to impress upon its pharmacists that many people with diabetes remain under-informed about the disease, to the point that about a third of all people with type 2 diabetes do not even know that they have this condition. By providing educational services in their stores, including appropriate referrals, Shoppers Drug Mart stresses that the pharmacist may positively affect patient outcomes. From a business perspective, Shoppers Drug Mart aims to demonstrate and position itself as offering superior diabetes care compared to the competition.

To promote commitment among its pharmacists to unsweetening blood and mitigating its effects, Shoppers Drug Mart publishes a newsletter, "Diabetes and the Pharmacist," under the Healthwatch® banner. By way of illustration of its contents, the May 1999 version contained information about the "Walk for the Cure" JDF fundraiser; told readers that 39 more of its pharmacists had elected to write the Diabetes Educator Certification Exam under the auspices of the Canadian Diabetes Association; provided information about two clinical trials seeking subjects that "you may wish to tell your patients about" (a clinical trial aiming to prevent or delay type 1 diabetes, and a clinical trial aiming to prevent kidney disease among people with type 1 diabetes); listed specials on diabetes-related "shopfront" merchandise that were slated for inclusion in upcoming issues of the national flyer; introduced Regenex®, the recombinant DNA gel that aids the healing of diabetic foot ulcers; highlighted target glucose and lipid levels set in the *1998 Clinical Practice Guidelines for the Treatment of Diabetes in Canada*; featured a common "patient question" about the use of herbs to control the sweetness of blood, to which a pharmacist with a PhD degree gave a page-long reply; and finally, presented evaluation results from the Diabetes Clinic Day.

Cultivation of the pharmacist-customer relationship took place alongside a very substantial reorganization of inventory control within the Shoppers Drug Mart / Pharmaprix group. In 1997, *Canadian Business* gave this initiative an Information Productivity Award. The lead paragraph of the story about the winners read:

You've got 700 stores, 300 million customer transactions a year and less than 18 months to reorganize it all. That's what Shoppers Drug Mart, Canada's largest retail drug chain, faced in 1997. Back then, Shoppers store owners across Canada did all their own buying from individual vendors and kept their own books. Then the company had a vision of the future, and even gave it a name: Vision '97. Shoppers Drug Mart built three regional distribution centres, developed a central accounting system and data warehouse, set up new point-of-sale systems for its stores and electronically linked its distribution centres stores and suppliers [using satellite technology]. Vision '97 became fully operational in January [1997], and the chain now has one of the most sophisticated data communications systems in the private sector. (Brandao 1997, 129)

Annual reports in the mid-1990s stressed that, in return for the \$250-million outlay to realize Vision 97, shareholders could expect improved market share and profitability:

Vision 97 is technology-based, but the program's ultimate focus is on customers. It is they who will benefit from lower selling prices and improved service, as redeployed staff devote more time to meeting customer needs. These advantages will help Shoppers Drug Mart / Pharmaprix to increase its market share and earnings in the years ahead. (Bloom 1995, 17)

Diabetes care, which Vision 97 promised to enhance, appeared as a flagship for customer loyalty in the 1995 annual report:

In 1995 Shoppers expanded our pharmacists' advisory role by inaugurating a counselling program aimed at patients with chronic diseases. The first disease targeted was diabetes and a system-wide training program enhanced our capacity to help diabetic patients monitor and achieve better control of their blood sugar levels. Private counselling is the fastest growing service area in pharmacy, and Shoppers' health-care advisory function will soon expand to include other diseases such as

cardiovascular disease, asthma, and arthritis. This amplified role will be stepped up as Vision 97's streamlining measures free our pharmacists to spend more time with customers. (Bloom 1996, 15)

In the end, Shoppers Drug Mart elected to develop a program focused on women's health rather than on arthritis because women of all ages form such a significant portion of their customer base: they tend to shop for themselves and for family members. Moreover, the three other main traffic-generating medical conditions – asthma, diabetes, and cardiovascular disease – are all potentially fatal, underscoring the importance of sound management.

Thus, by the mid-1990s, Shoppers Drug Mart / Pharmaprix aimed to deploy its pharmacists as the vanguard of customer service. Relieved of the minutiae of merchandising and accounting, the pharmacist would be “free” to concentrate on providing services of professional calibre. In doing so, the local pharmacy would embody a “health destination,” and while in the stores, customers could attend to other needs and “impulses.”

Annual reports from the late 1990s and 2000 portrayed this renewed focus on professionalism as a source of competitive advantage. Total sales grew from \$3.3-billion in 1995 to \$4.3-billion in 1999; total earnings increased from \$101-million in 1995 to \$277-million in 1999. By 1999, prescriptions, OTC medications, and medical supplies together accounted for 55% of total sales. “Nutraceuticals” – vitamins, minerals, herbal remedies, and other dietary supplements – had become more significant and increasingly, occupy a demarcated area near the dispensary. After the company installed such kiosks, vitamin sales increased 40% (Hanson 1999). A renovation program currently underway aims to facilitate “patient-pharmacist dialogue” and improve the “customer's shopping experience” by introducing waiting areas near dispensaries, semi-private counselling areas, and private consultation rooms, among other reforms (Bloom 1999, 14). Rather than slashing dispensing fees, Mr Bloom told investors, “Shoppers Drug Mart's approach is to demonstrate to payers that

pharmacy services, properly managed, lead to better patient outcomes and lower overall health-care costs.” (Bloom 1999, 13)

Complementing the intensification of pharmacists’ professional development and services related to select health concerns, among them diabetes, Shoppers Drug Mart advertising has increasingly stressed that its retail pharmacists can help customer-patients secure health and well-being. In 1993, Shoppers Drug Mart decided to review its English-language advertising campaign, worth about \$20-million annually, which unleashed a veritable “feeding frenzy” in the quest to land the coveted account (Scotland 1994). A single agency had held the account for twenty-seven years. For the previous ten years, Shoppers had deployed star power, which seemed to be fading:

Management at Shoppers quite rightly guessed that its advertising was due for an overhaul. TV spots, starring the husband-wife team of Michael Tucker and Jill Eikenberry from *L.A. Law*, had grown tired and limp. Typical ads would show the pair cavorting in a store aisle, flirting over greeting cards, cosmetics or prescription drugs.

The campaign was ridiculed by other agencies as being ineptly executed and too cute by half. By comparison, Kert’s previous ads starring Beatrice Arthur of *Golden Girls* fame seemed wittier, fresher and more daring. Arthur’s trademark double-takes and snappy one-liners had been masterfully exploited. (Scotland 1994)

The new television advertisements aimed to polish Shoppers’ image as caring, competent and convenient, reported *The Financial Post*:

The showbiz sheen of past campaigns is gone, replaced with a patina of realism.

One new television commercial, featuring naked mannequins as models, urges women to do monthly breast self-examinations.

Another shows a man making an early-morning run for medicine for his sick child. The spot highlights a new 1-800 number

consumers can call for the location of a Shoppers store open 24 hours a day.

A third, decidedly more upbeat, commercial is set in a Shoppers cosmetics department. A woman, evidently suspecting her lover, asks the cosmetician to do some sleuthing. She is happy to oblige, correctly determining the brand names of a lipstick smear, bleached hair and perfume. (Scotland 1993)

With Wal-Mart and other large-surface retailers opening pharmacy departments, the onus was on Shoppers Drug Mart to demonstrate why customers should continue doing business with them, and pay a premium dispensing fee on prescriptions for the privilege. The company responded by promoting concern for the health and emotional lives of their customers.

In 1992, the company began distributing fact sheets about each new prescription, billed as Healthwatch® Reminders (Bloom 1995). These PILs, for “patient information leaflets,” are currently prepared under contract for Shoppers Drug Mart by a subsidiary of the Hearst Corporation based in California (Foss 2000b). The popularity of this initiative, reinforced with advertising and in-store promotions, has helped Shoppers Drug Mart build brand name recognition for its pharmacy services under the Healthwatch® banner. As provincial governments computerize prescription claim records, pharmacists are positioned to detect potentially-harmful drug interactions, as well as efforts to fill the same prescription more than once. In fact, alongside Shoppers Drug Mart, the governments of Ontario and Quebec won Information Productivity Awards for computerizing their drug plans (Brandao 1997). Shoppers Drug Mart trumpets the health advantages for consumers gained by computerization as part of their Healthwatch® System.

The establishment of diabetes and other “disease state” management programs from 1996 onwards extended the scope of the Healthwatch® brand:

By focusing on specific disease states such as diabetes, asthma or heart disease, and by fostering a strong connection to Shoppers Drug Mart, we built trust across the board – and not

just from people suffering from these diseases. Now we could be seen as managers of health outcomes, reflecting the consumer trend towards self-care. (Ralston 2000)

While the company has historically spent a large part of its advertising budget on television spots, it currently promotes the Healthwatch® brand in magazines as well. For example, it advertises in *Diabetes Dialogue*, the Canadian Diabetes Association's publication for adults, as well as in "mainstream" magazines. "Now that consumers are aware of Healthwatch, its services are being copied by the competition, reinforcing SDM's [Shoppers Drug Mart] leadership position," a spokesperson has maintained. "Healthwatch advertising shows a commitment to pharmacy, thereby increasing its value to the consumer. It has allowed Shoppers to develop a pharmacy brand – an industry first." (Ralston 2000)

Indeed, other companies involved in the drugstore business are self-consciously trying to duplicate the Healthwatch® success story by emphasizing pharmacists' professionalism and heart-felt concern for their customers.

Under the PharmAssist® banner, a self-described "once-sleepy wholesaler" has aired a series of television spots showing real-life pharmacists, whom it supplies, going above and beyond the call of duty. One spot features a pharmacist from British Columbia climbing over rockslides to deliver medication to a hospital; another features a pharmacist awakened by an emergency call, opening her store in the dead of night, and delivering supplies to a maternity ward. The true stories, judged the best of 50 sent in by affiliates, represent an attempt to take back some of the drug "moral high ground" won by Shoppers Drug Mart's Healthwatch® campaign (Brent 1999).

Current advertisements for the Quebec-based Jean Coutu chain, which often feature its founding pharmacist, promise, "You'll find it all...even a friend" (*On trouve de tout...même un ami.*). Signs with the slogan, "We take your health to heart" (*Votre santé nous tient à coeur*), appear in store windows and inside the stores themselves. The Jean Coutu chain numbers nearly 300 stores in Canada, mostly located in the province of Quebec, and it operates more than 250 stores in the New England region of the United States. Similar to Shoppers Drug Mart and

Pharmaprix locations, many stores in the Jean Coutu group have recently undergone renovation to promote dialogue between pharmacists and customers, including the Jean Coutu outlet nearest my home. It now features a pharmacist desk in the over-the-counter medication section; closed offices and a waiting area with 20 chairs adjoining the dispensary; and glassed-in cabinets built into the dispensary containing such technologies as blood glucose monitors, pen-like syringes that accept insulin cartridges, pregnancy tests, and blood pressure kits designed for home use.

Faced with renewed competition from other drugstores promoting the retail pharmacists' expertise and caring concern, Shoppers Drug Mart currently aims to "sweeten" their customers by extending a form of credit, similar to the local grocery store in the Aboriginal community of Belyuen, Australia (cf. Povinelli 1993, 195). In the case of Shoppers Drug Mart, the credit extended to customers takes the form of "points," not money. By issuing points that count towards "rewards" with almost all purchases, the Optimum Program® introduced in 2000 aims to secure loyalty to the chain. It may also prompt customers already in one of their stores – to pick up a prescription or a pack of cigarettes, for example – to add items to their shopping baskets. Customers accumulate points for each prescription filled in all provinces except one, but the program excludes tobacco products and lottery tickets. Special offers currently include bonus points (if the customer purchases two packages of certain kind of mascara, for example) as well as price reductions. Within weeks of its introduction, millions had enrolled and received their "loyalty cards." Jean Coutu has also introduced a reward program. These initiatives piggyback on point-of-sale data, generating a file for each individual member. The more customers buy, the more credit they accumulate, the more beholden they are to the enterprise; and the more beholden the enterprise is to them.

## NICOTINE, PHARMACOLOGY, AND PHARMACIES

As hinted in the paragraph above, while “positioning” pharmacy as a health profession, many Shoppers Drug Mart stores currently sell tobacco products. In fact, a conglomerate steeped in the tobacco-nicotine business owned the company from 1978 until 2000.

In recent years, tobacco executives have come under renewed attack because evidence that they deliberately misled customers, potential customers, and governments has been made public. Little scrutiny has attended tobacco company board members, nor shareholders, nor executives who have led “non-tobacco” subsidiaries, nor tobacco-nicotine retailers. Yet the tobacco-nicotine industry does not profit in a vacuum. In contemporary Canada, cigarettes seduce as much by money as by the pharmacology of nicotine.

By highlighting how the political economy of sweet blood and of nicotine currently overlap, this chapter extends a respected analysis of the tobacco-nicotine industry which also focuses on the Canadian situation (Cunningham 1996). The embrace of “sweet demographics” by Shoppers Drug Mart in the 1990s highlights the extent to which the drugstore business has hinged upon pharmaceutical sales *and* tobacco-nicotine sales (which, in the long term, generate pharmaceutical sales). This case study raises questions about the implications of investing profits from the tobacco-nicotine industry into other lines of business, particularly health care.

The relationship between Shoppers Drug Mart and the tobacco industry reflects what business textbooks call “integration,” since tobacco consumption helps produce many of the ills that pharmaceuticals seek to control. Cigarettes and smokeless tobacco products cause blood glucose levels to spike and may contribute directly to the onset of diabetes (Nakanishi et al. 2000; Persson et al. 2000; Rimm et al. 1993). Smoking predisposes people with diabetes to “complications”: heart disease, peripheral vascular disease, and lower limb amputations (Canada. Health 1999c, 3). Nicotine, the pharmacologically-active

substance in tobacco products, multiplies the impact of cardiovascular risk factors, among them sweet blood.

As many Canadians with diabetes as without diabetes, aged 35 to 64, report that they smoke on a daily basis (Canada. Health 1999c, 34). Current smoking rates among Aboriginal peoples in Canada, among whom type 2 diabetes has become so prevalent over the past few decades, are particularly high. Approximately two thirds of Aboriginal adults in Canada smoke, compared to less than one third of all non-Aboriginal adults (Reading 1999).

### *Success and Succession*

Here is how the 1988 authorized biography of company founder Murray Koffler explains the decision to sell his pharmacy chain to Imasco, a Canadian-yet-multinational company rooted in tobacco:

He had passed the age of fifty, and recalled how unprepared he had been as a seventeen-year-old to take charge of the two family drugstores when his father died at forty-seven. So [in 1975] he and [wife] Marvelle assembled their five children for an all-day estate-planning session around a table in a suite at the Quatre Saisons Hotel in Montreal where they had all gathered for a wedding. [Koffler also co-founded the Four Seasons Hotel chain.] He laid it on the line and said, "Let's talk about our futures".... They debated the issue all day and that night decided in a vote they favoured selling the business and choosing career opportunities of their own.... The following month, Koffler arranged with eighteen key members of his management team to hold a similar freewheeling discussion at [his] Jokers Hill Farm.... They, too, agreed unanimously that to sell Shoppers Drug Mart would be the wisest move.

Koffler was charged with the task of finding an appropriate purchaser. Eventually, on May 1, 1978, after discussing the offers of four other potential buyers, he sold the Shoppers chain of 364 outlets to Imasco Limited for approximately \$70 million.

Of that total, 60 per cent was in cash and 40 per cent in Imasco shares. The sale put Koffler in the position of being one of the largest individual shareholders of what is today a multinational consumer products and financial services conglomerate. It is expected to gross well over \$10-billion in 1988.

Koffler selected Imasco for several reasons. First of all, the Montreal-based company had a solid financial foundation. Its major money-earner, the eighty-five-year old Imperial Tobacco Tobacco Ltd., produces more than half of all cigarettes sold in Canada; among them are such name brands as Player's, du Maurier, Peter Jackson and Matinee. Though 40 per cent owned by Britain's B.A.T. Industries – British-American Tobacco, which operates tobacco factories in more than fifty countries – Imasco was solidly Canadian in its outlook and board membership. Koffler liked its sponsorship of worthy Canadian causes; among them are the Imasco Scholarship Fund for Disabled University Students and the du Maurier Council for the Performing Arts, which supports theatre, music, and ballet. Koffler liked the way it had faced the fact that tobacco was not a growth industry and had taken steps to diversity in the retail field. Its totally owned subsidiaries included the United Cigar Store chain in Canada and the Hardee's fast-food restaurant chain in the United States. To top the icing on the cake, it had acquired the Canadian chain of sixty Top Drug Marts, which could be nicely integrated into the Shoppers family of stores. Most important of all, Koffler liked the cut of the job and the managerial style of Imasco's board chairman. He met Paul Paré in a meeting at Imasco's unpretentious Montreal headquarters. With Paré smoking part of his daily allotment of twenty mild Matinee cigarettes and Koffler puffing his ritual morning Player's, they took to each other instantly. (Rasky 1988, 306-308)

In what might constitute the ultimate in brand loyalty, Koffler decided to sell Shoppers Drug Mart to the manufacturer of his preferred brand of cigarettes. The financial fundamentals were right, Shoppers' executive ranks would retain day-to-day autonomy, and Koffler himself would join the Imasco board.

An alliance between a pharmacist and a cigarette manufacturer seems dissonant, given public knowledge about the health risks posed by tobacco and in light of recent efforts to promote "community pharmacy" as a professional practice that can improve health. Yet throughout the twentieth century, the drugstore business entwined with the tobacco-nicotine industry.

An anecdote marshalled by Murray Koffler's biographer illustrates these interconnections. After the Shoppers Drug Mart chain went public in the late 1960s, Mr Koffler's long-time tobacco supplier "sweetened" him by giving unusually long credit terms. Koffler recalled:

He knew he was going to get paid, but he felt that [extending credit] was the way he could best maintain the faith we had in each other. He went out of the way to get us the best tobacco and confectionery deals that would help our chain grow. On our part, we played a role in adding a lot of volume to his business, which helped his company grow. (cited in Rasky 1988, 136-137)

Another anecdote, recounted by Mr Koffler's biographer to impress upon the reader the wisdom of his subject's succession strategy, underscores the pivotal role that tobacco-nicotine profits played in more than doubling the size of the Shoppers Drug Mart group between 1978 and 2000. This story features David Bloom (who succeeded Murray Koffler as Shoppers Drug Mart CEO in 1983, at the age of 39) and Paul Paré's chosen successor at Imasco, Purdy Crawford:

Bloom remembers inviting Imasco's new general to accompany him on a trip in the pre-Christmas season of 1985 to inspect the Shoppers troops deployed in their drugstore trenches right across Canada. Crawford instantly accepted. It turned out to be a seven-day-and-seven-night endurance test. They were usually up at seven for breakfast meetings and got to bed well past midnight.

They blitzed through 100 stores in twelve cities, met about 150 pharmacists and regional management teams, and plunged into a wicked blizzard in Newfoundland.

“On Saturday at noon we finally both fell asleep in chairs at the last airport,” recalls Bloom. “I felt we passed the test, emotionally and physically, in flying colours. And when Purdy woke up, he told me, ‘You can be proud of the wonderful family spirit of your people. Shoppers has won our confidence and you can count on our 100 per cent support. Imasco is prepared to set aside growth capital so Shoppers can achieve the goals you’ve set for it. The opportunities are endless and the tomorrows are bright.’” (Rasky 1988, 318-319)

By 2000, the Shoppers Drug Mart chain numbered 837 locations, 473 more than when Imasco acquired it in 1978 – thanks in no small part to Imasco’s “deep pockets,” courtesy of its flagship, Imperial Tobacco.

### *The Diversification Era and Its Demise*

In 1999, Imasco announced that it would sell off all of its subsidiaries and revert to the Imperial Tobacco name, reversing over thirty years of efforts to diversify beyond the tobacco-nicotine business. “After the smoke cleared, there was no cure for the tobacco profit habit,” read the headline of the *Financial Post* story announcing that all Imasco assets except Imperial Tobacco would be sold because the parent company, British American Tobacco (BAT), had elected to renew its focus (Olive 1999). Imperial Tobacco products currently hold 64% of the Canadian cigarette market; its du Maurier and Player’s brands are the first and second most popular brands sold in Canada (Imperial Tobacco Canada Limited 2000, 1).

The publication of the 1964 US Surgeon General’s report on smoking and health sparked the diversification era (Belsito 1992). This report found that cancer causes lung cancer in men and suggested that this association likely holds for women, too. It also took note of epidemiological evidence suggesting that

**Figure 38:**

**Sale on cigarettes at Shoppers Drug Mart**



Adapted from Imasco's Annual Report for 1984, p.15

## Figure 39:

### Shopper's Drug Mart / Pharmaprix Milestones

1921	Leon Koffler, father of Shoppers Drug Mart® founder Murray B. Koffler, opens the first of two family pharmacies in Toronto, Ontario, Canada.
1941	At age 17, Murray Koffler succeeds his father.
1955	Tom Roe becomes Murray Koffler's first Associate pharmacist.
1962	Murray Koffler opens the first Shoppers Drug Mart at Shoppers World Plaza in Toronto.
1968	Shoppers Drug Mart becomes a public company with 52 stores in Ontario.
1970	Stores open in Manitoba, British Columbia, Alberta, Saskatchewan and the Yukon.
1972	The first Pharmaprix store opens in Quebec as part of the Shoppers Drug Mart system.
1974	Shoppers Drug Mart absorbs Lord's Supervalu Pharmacies in Atlantic Canada.
1978	Shoppers Drug Mart becomes a wholly owned subsidiary of <b>Imasco</b> Limited.
1983	David Bloom becomes President and Chief Executive Officer.
1986	Murray Koffler retires; David Bloom becomes Chairman; Herb Binder is appointed President and Chief Operating Officer.
1992	Shoppers Drug Mart launches the HEALTHWATCH System®, providing patients with HEALTHWATCH Reminder®, a print-out of information about their prescription drugs, including possible side effects and cautions.
1993	Shoppers Drug Mart shifts its English-language advertising account and lays plans to intensify connections between the stores, head office, suppliers, and new distribution centres.
1996	Shoppers Drug Mart introduces HEALTHWATCH® programs targeting three common and potentially fatal diseases: <b>diabetes</b> , <b>asthma</b> , and <b>heart disease</b> .
1999	After two years of market research, systematic renovation of the stores begins.
2000	<ul style="list-style-type: none"><li>▪ Shoppers Drug Mart announces the completion of its acquisition by an investor group led by an affiliate of Kohlberg Kravis Roberts &amp; Co. In addition to KKR, the investor group includes Bain Capital Inc., CIBC World Markets, Charlesbank Capital Partners, LLC., DLJ Merchant Banking Partners, The Ontario Teachers' Pension Plan Board and the Senior Management &amp; Pharmacist/Owners of Shoppers Drug Mart. Stan Thomas (who joined Shoppers Drug Mart in 1986 as Senior Executive Vice President, Marketing) becomes President and Chief Operating Officer.</li><li>▪ Within months of its launch in September 2000, the Optimum Program™ became one of the largest customer loyalty programs in Canada.</li></ul>

cigarette smokers have higher rates of cardiovascular disease. It did not deem tobacco as an addictive substance – just “habituating.” Not until 1998 did the US Surgeon General declare nicotine to be an addictive drug (see Glantz et al. 1996, 48-48, 58).

After Imasco put its non-tobacco subsidiaries on the auction block, the financial pages documented intense interest in Shoppers Drug Mart from many parties (Gibbens 1999; Leger 1999a). A investor group led by a private firm headquartered in the United States and England submitted the successful bid, offering \$2.6-billion in cash (Leger 1999b).

Throughout the 1980s and the 1990s, many investors embraced Imasco. “After all, people will smoke, eat hamburgers and shop at their local drug store however the economy performs” (Gold 1988). “I believe diversification is appropriate, but investors seem to like to be in cigarettes,” one analyst said when asked to account for Imasco’s success (cited in Ewart 1993). “It’s probably the most politically incorrect industry to bet on until the fur industry goes public, but investors’ love affair with tobacco has not cooled despite lawsuits and renewed threats of government regulation,” noted another article on the fortunes of the tobacco-nicotine industry. It continued, “Looking at it unemotionally, investors have good reason for their faith. Tobacco companies are veritable cash cows. Nowhere is this more true than in Canada...” (Brent 1995)

“In an age when smoking is a dying pastime, Purdy Crawford, [then] 61, chief executive of...Imasco Ltd., can’t get the conglomerate to kick its nicotine habit,” a 1993 feature observed. “Despite his best efforts, Imasco remains hooked on tobacco. It derives half its operating profit from the country's most successful cigarette manufacturer, Imperial Tobacco Ltd.” (Gittins 1993).

Pharmacists Murray Koffler and his handpicked successor, David Bloom, were fixtures on the Imasco board while Shoppers was an Imasco subsidiary. Reflecting its blue-chip status, members of Imasco’s board also included Canada’s current Finance Minister, Paul Martin (1985-1987); Judy Erola, a Liberal party cabinet minister under Trudeau in the 1970s and president of the

Canadian Pharmaceutical Manufacturers Association in the 1990s; and Robert Pritchard law professor and former principal at the University of Toronto, who was recently selected to head up Torstar Corporation, publisher of the *Toronto Star*.

### ***Going to BAT: Profiting from Nicotine***

At the end of the diversification era, BAT shareholders owned 31% of Imasco, and thus, in effect, 31% of Shoppers Drug Mart (Statistics Canada 1998, 34). The nexus that incorporates BAT, Imperial Tobacco, Shoppers Drug Mart, and millions of human bodies – through which so many health problems have been produced and treated – raises many questions. When did tobacco company executives learn of their product’s capacity to addict and to shorten lives? How did they respond to this knowledge? How did ties to the tobacco industry affect business for subsidiaries such as Shoppers Drug Mart, other than providing access to “deep pockets”?

On 23 June 1994, in a televised session before the US House of Representatives Subcommittee on Health and the Environment, Thomas Sandefur, CEO of BAT’s American subsidiary, the Brown & Williamson Tobacco Corporation (B&W), testified, “I do not believe that nicotine is addictive.” The other six American “big tobacco” CEOs made similar statements – including Andrew Tisch, CEO of the Lorillard Tobacco Company and son of Larry Tisch, head of the CBS television network and Lorillard’s co-owner.

Citing “libel chill,” CBS declined – initially – to air statements in which Dr Jeffrey Wigand, formerly B&W’s director of research and development, alleged that Thomas Sandefur had lied (see Brenner 1996). Dr Wigand also testified to this effect in a legal case brought by the State of Mississippi to recoup the costs of treating sickness caused by smoking. Other states filed similar lawsuits. The acclaimed film *The Insider* (1999) dramatizes these events and the smear campaign to discredit Dr Wigand that ensued after he became a whistleblower. Canada’s Minister of Health, Allan Rock, recently announced that Dr

Wigand would provide consultation services, to the chagrin of Imperial Tobacco (Canada. Health 1999d; Imperial Tobacco 1999).

Dr Wigand's public statements about the tobacco-nicotine industry, and more specifically B&W and the BAT clan, find support in the many internal documents that entered the public domain in the 1990s (see Cunningham 1996; Glantz et al. 1996; Health Canada 1999). It is now clear that the executive ranks of BAT *and its subsidiaries* knew in the early 1960s that nicotine is addictive and that tobacco substantially increases the risk of cancer and cardiovascular disease, among other health problems.

At a research conference held in Southampton, England, in 1962, the keynote address delivered by an executive in the research and development division of BAT included the following remarks:

One result of the recent public discussion on smoking and health must have been to make each of us examine whether smoking is *just a habit of addiction* or has any positive benefits. It is my conviction that nicotine is a remarkably beneficent drug that both helps the body to resist external stress and also can as a result show a pronounced tranquillising effect...and it is a fact that under modern conditions of life people find that they cannot depend just on their subconscious reactions to meet the various environmental strains with which they are confronted. (cited in Glantz et al. 1996, 61, emphasis added)

In this address, Sir Charles Ellis also said that a researcher whom he had contracted to study nicotine believed "that although nicotine undoubtedly affects the cardiovascular system, these effects are probably quite innocuous for normal healthy people" (Glantz et al. 1996, 98). The conference report included a detailed summary of the discussion following this address. Debate centered on directions that BAT research should take; nobody disagreed with the characterization of nicotine as addictive, nor that it might affect the cardiovascular system. The Imperial Tobacco Company of Canada was represented at this conference (Glantz et al. 1996, 278).

In 1963, after deliberation and consultations with BAT brass, B&W executives elected to withhold from the US Surgeon General research commissioned by the parent company on the pharmacology of nicotine. These studies suggested that, deprived of nicotine, chronic smokers “are left with an unbalanced endocrine system,” yet do not cope any better with stress than non-smokers (cited in Glantz et al. 1996, 68-69). “One can speculate, with enormous regret, how different that 1964 report would have been had the tobacco companies shared their research with the Surgeon General’s Advisory Committee,” wrote Dr C. Everett Koop, US Surgeon General from 1981 to 1989, after BAT internal documents dating from the 1960s were smuggled into the public domain (Koop 1996).

During the 1960s, BAT internal documents show that executives hoped to make cigarettes “safe” – that is, discover and eliminate the nefarious components of cigarette smoke, while retaining the purportedly “beneficial” effects of nicotine. Notably, the very design of their research studies during this period indicates that they acknowledged the carcinogenic properties and other deleterious effects of tobacco. But in the 1970s, they largely abandoned the search for a “safe” cigarette, focusing instead on marketing “light” and “mild” products. The health problems seemed intractable, and any genuine solution would involve admitting that conventional products posed health hazards (Glantz et al. 1996). In fact, in a letter dated 29 December 1989, a BAT executive admonished Imasco CEO Purdy Crawford for advocating that “we should give a higher priority to projects aimed at developing a ‘safe’ cigarette” (cited in Health Canada 1999, 40).

In light of the knowledge available to Imperial Tobacco executives about the pharmacology of nicotine, from the 1960s on, it is instructive to compare how the company currently portrays addiction and its future prospects. The company web site buttresses “social-construction-of-disease” arguments with statistics:

As the use of the term addiction has broadened over the last quarter-century, we agree that smoking can be described as an addiction under this broad definition. What we know is that many smokers find it difficult to quit smoking. Yet millions of

smokers have quit, and the vast majority has done so without any outside assistance, medical or otherwise. Today in Canada there are more ex-smokers than smokers. (Imperial Tobacco 2001)

A recent financial report focuses squarely on the demographics of smokers, assumed stable, to encourage investment: “While Imperial Tobacco estimates that there are over six million Canadian adult smokers, this long-term trend is expected to continue.” (Imperial Tobacco Canada Limited 2000). Its mission statement appears both in this report and on the web site: “Imperial Tobacco’s mission is to compete successfully for market share in any market the Corporation enters, by satisfying adult smoker preferences in a manner that is profitable, sustainable, and increases the value of the Corporation.”

### *Nicotine in Chains: Pharmacists and “Choice”*

In 1989, *The Financial Post* reported that the president of the Canadian Medical Association threatened to be “hazardous to cigarette manufacturers’ health,” and to the bottom lines of many pharmacies. Dr John O’Brien-Bell was urging Canada’s physicians to suggest that their patients not fill prescriptions at pharmacies where tobacco was sold. Dr O’Brien-Bell, a former pack-a-day smoker, used to “go out at two in the morning and drive across town to put my money in a machine if I hadn't got a cigarette in the house” (cited in Drohan 1989). Arthur Konviser, Shoppers Drug Mart senior vice-president, said in response that the drug store chain would not act as a “moral or social arbiter” for consumers. The article underscored that Imasco, the parent company of Imperial Tobacco, also owned the drugstore chain (see Drohan 1989).

*The Financial Post* also reported that the CMA decided to call for a boycott of pharmacies that sell cigarettes after Shoppers Drug Mart sponsored a television program decrying drug addiction in Canada. CMA President John O’Brien-Bell sent a letter to congratulate Shoppers Drug Mart for this act of corporate responsibility. O’Brien-Bell went on to accuse the company of hypocrisy by “continuing to sell products which are known to be the single biggest cause of heart disease.” The CMA decided on the boycott strategy after

Shoppers Drug Mart declined to allow CMA representatives to meet with the company board. Said a CMA spokesperson, “When it came down to selling tobacco, we came from a health perspective while they [Shoppers Drug Mart] came from the perspective of a retailer.” Voicing the ethos that would later imbue Shoppers’ Healthwatch© brand, the CMA spokesperson also said, “Our perspective is that a pharmacy is a special store where doctors and patients go for professional advice.” (cited in Evans 1989)

During the 1980s and 1990s, Shoppers Drug Mart attracted criticism for prominently displaying tobacco products, regularly putting tobacco products on sale, and advertising these specials in its national flyer (Elis 1989; Cunningham 1996, 259). In an interview with *The Financial Post*, the Executive Director of the Canadian Pharmacists Association said that the organization had been concerned about the sale of tobacco products in drugstores for many years, mounting a campaign in 1986 that led 771 pharmacists to quit selling tobacco products. But this spokesperson for the Canadian Pharmacists Association added that while retail tobacco margins are small, the products can be the “most powerful” loss leader in attracting consumers into the pharmacy (cited in Evans 1989).

Several non-governmental organizations besides the Canadian Medical Association and some politicians have pushed for greater regulation of the tobacco industry. For example, Canada’s current Minister of Health, Allan Rock, recently threatened to force the tobacco industry to cease using words such as “light” and “mild” on cigarette packages. If the federal government fights off an expected legal challenge, some of the most popular product lines will have to be renamed (Clark 2001). In 1988, despite legislation on Ontario’s books that forbade tobacco sales to buyers under 18, minors “successfully” purchased cigarettes in 25 out of 30 Shoppers Drug Mart stores that they approached; the Student Movement Aimed at Restricting Tobacco (SMART), started by University of Toronto law students, organized the sting operation (Cunningham 1996, xi). As of 1999, the Canadian provinces of Ontario, Quebec, and New

Brunswick forbid the sale of tobacco-nicotine products in drugstores (Bloom 1999, 14).

In the interests of brevity, the discussion that follows will concentrate on the response by Shoppers Drug Mart to Ontario's leadership in banning tobacco sales in pharmacies (see also Cunningham 1996, 159). Yet the defence of tobacco-nicotine sales by Shoppers Drug Mart executives and associate pharmacists in Ontario hardly represents an isolated case.

The Jean Coutu group mounted a legal challenge analogous legislation in Quebec. Figure 40 caricatures the founder, an icon in the Quebec business world, as selling both cigarettes and the remedies for diseases caused by cigarettes. "Tobacco is an important revenue source for the pharmacists," said Jean-François Coutu, the founder's son and current CEO, told the *Financial Post* in an interview. "Let's let the public decide whether they want to buy cigarettes." (cited in Dougherty 1997)

On 22 November 1993, the Government of Ontario introduced legislation banning the sale of tobacco products from vending machines, hospital premises, and drugstores. "This legislation will be economically crippling to pharmacy," Shoppers Drug Mart executives said in a prepared statement. "All the citizens of Ontario will ultimately pay the price for this government's irresponsible action." (cited in Scotton 1993). *The Financial Post*, however, reported that smoking-related health care bills cost the province \$3.5-billion annually, while provincial tax revenues from the sale of tobacco products total \$2.7-billion (Scotton 1993).

A group of more than 500 Ontario pharmacists, many part of the Shoppers Drug Mart chain, tried but failed to obtain an injunction that would have allowed them to continue selling tobacco-nicotine products (Fowlie 1993). Ontario Court Judge Stephen Borins ruled that the public benefits of the act far outweigh any commercial consequences suffered by the pharmacists. To his mind, pharmacists have an ethical responsibility to protect their customers from the hazards of cigarette smoking. Like the CMA spokesperson cited above, the judge voiced the

**Figure 40:**  
**Editorializing cigarette sales in**  
**Jean Coutu drugstores**



“We sell the owie! We sell the remedy.”

“Happy St-Jean Baptiste Day!”

- 24 June, the day chosen by the Roman Catholic Church to honour Saint John the Baptist, is Quebec’s national(ist) holiday.

Source: <http://www.frenzo.com/caricatu/caricomp/compihtm/06-24-98.html>

main message of Shoppers' then-brand-new Healthwatch© brand. "Pharmacists are part of the health-care system in this province," he said (cited Fowlie 1993).

Just as the ban on cigarette sales in Ontario pharmacies came into effect, Shoppers Drug Mart introduced its diabetes awareness and counselling program. Each of these developments receives attention, on separate pages, of David Bloom's annual report to Imasco shareholders (Bloom 1996). The year before, Mr Bloom had noted that the prohibition on the sale of tobacco products in Ontario pharmacies "will have a negative impact on our 1995 earnings." But, he said, "Ultimately, we believe that the loss of tobacco revenues, combined with pressure on prescription prices, will result in increased market share for Shoppers Drug Mart / Pharmaprix, as we are better positioned than some other chains and independent pharmacies to absorb these changes." (Bloom 1995, 16-17)

The defense of tobacco-nicotine sales in drugstores – by the Jean Coutu chain, by Shoppers' brass, and by more than 500 individual pharmacists across Ontario – underlines that Imasco shareholders have not stood alone in profiting from "adult smoker preferences," not to mention teen smokers. Yet the affiliation between BAT, Imperial Tobacco, and Shoppers Drug Mart under the umbrella of Imasco may help explain why Shoppers Drug Mart did not voluntarily eliminate tobacco-nicotine from its "product mix" during the 1990s, when the chain was also promoting the pharmacist as a health professional.

An internal memo entitled "Legal Considerations on Smoking and Health Policy," warns that BAT's non-tobacco subsidiaries must adhere to the parent company's stance on smoking and health:

The issue is controversial and there is no case for either condemning or encouraging smoking...It may be responsible for the alleged smoking related diseases or it may not. No conclusive scientific evidence has been advanced and the statistical association does not amount to cause and effect. Thus a genuine scientific controversy exists.

The Group's position is that causation has not been proved and that we do not ourselves make health claims. Consequently the

Group cannot participate in any campaigns stressing the benefits of a moderate level of cigarette consumption, of cigarettes with low tar and/or nicotine deliveries or any other positive aspects of smoking except those concerned with the dissemination of objective information and the right of individuals to choose to smoke...

Non-tobacco companies in the Group must particularly beware of any commercial activities or conduct which could be construed as discrimination against tobacco manufacturers (whether or not involving companies within the Group), since this could adversely affect the position of Brown & Williamson in current US product liability litigation in the US. If in doubt, companies should not hesitate to consult their inhouse legal counsel, or BAT Industries Legal Department, who have up-to-date information on the legal situation affecting the tobacco companies. (cited in Glantz et al. 1996, 274)

Taking into account the US legal system, this memo therefore advises BAT's "non-tobacco" subsidiaries the world over to refrain from claims about the impact of smoking on health and from encouraging people to smoke less, never mind encouraging them to quit. A fact sheet that Shoppers' central office endorsed in the late 1990s for distribution to the general public, however, expressly discourages people from smoking, whether they have diabetes or are "trying to prevent it" (see Figure 37).

I, for one, feel disquiet about the extent to which tobacco-nicotine profits both fuelled Shoppers Drug Mart's drive to become Canada's largest drugstore chain and capitalized the establishment of Healthwatch©-branded services such as diabetes education, services that allowed Shoppers Drug Mart to claim "the moral high ground." My discomfort throws into relief ambivalence about the capacity of money to so transform that but a trace of its past remains, and that trace is often faint indeed. Money can be laundered, of that "we" are all aware. Once its past has been revealed, however, money exhibits a moral tinge, for better or for worse. Given the enormous profitability of cigarettes, where is all that "ashen" money to

go? What will it yield? What should it yield? Throughout the “diversification era,” BAT and Imasco/Imperial Tobacco ploughed tidy sums into Shoppers Drug Mart and other “non-tobacco” ventures. Currently, their profits either transfer to shareholders as dividends or they remain in tobacco – continuing to produce problems, such as “complications” arising from sweet blood, that the pharmaceutical industry, physicians, pharmacists, other health professionals, and afflicted individuals will later try to remedy.

### **DEMOGRAPHICS AND “HEALTHY ECONOMIES”**

Pharmaceuticals and tobacco products both highlight that political economy must take into account the possibility of absorbing “mere” things into individual human bodies. While items such as cigarettes and insulin clearly constitute merchandise, my investigation of how the Canadian drugstore industry entwines with the tobacco industry, with the pharmaceutical industry, and with epidemiology lends nuance to the properties conventionally assigned to commodities.

Through consumption, tobacco products and pharmaceutical products articulate with human physiology, to the point of affecting the length of human lives. Similar to food, people so depend on these products that their steady supply has become a significant concern for many businesses. Through regular purchases as well as regulations, such as those governing the legal sale of pharmaceutical and tobacco-nicotine products, commodities may become associated with particular vendors. By branding goods and services with names, with identities, corporations try to ensure that the moment of purchase does not wholly sever commodities from suppliers. The identities cultivated by corporations usually reflect market research on how various “types” of consumers use and think about what they buy. These statistically-fashioned “types” combine physiological information (sweet blood? smoker?) with “social” characteristics such as age, income, and insurance coverage.

Under such conditions, social theory suggesting that, by definition, commodities remain detached (alienated) from people under capitalism seems glib. As illustrated by the interconnections between population health, the tobacco-nicotine industry, the pharmaceutical industry, and the drugstore business, in different ways and for different reasons, manufacturers, vendors, and customers routinely count on one another.

Human bodies, analogous to prisms, convert dollars into sweet blood through consumption. When blood becomes *too* sweet, it converts back into dollars for goods and services that promise to lengthen and otherwise improve lives, spinning countless objects into circulation and prefiguring the geographic and social positioning of many groups of people, of entire populations. Through serial possession and consumption of the “necessities of life,” consumers reproduce manifold kinship relationships as money and statistics flow. In the case of diabetes, the sweetness of blood interfaces with built environments, social networks, “health risks,” and technologies designed to aid in lessening these risks.

English-speaking Canadians may not like to imagine themselves as commodifying people and “we” do not, at least in the vernacular, talk of human bodies as piggy banks or store houses, but many of “us” routinely conceive of groups of people as “cash cows” (cf. Strathern 1996, 517). When I sketched how Shoppers Drug Mart had embraced diabetes education, one interlocutor said, “They [people with diabetes] are cash cows.” Pharmaceutical companies increasingly regard people with dangerously sweet blood as “cash cows.” Investors, similarly, regard tobacco companies, and smokers, as “cash cows.”

Money to treat medical conditions such as sweet blood and nicotine addiction comes partly from the pockets of individuals, but also from governments and insurance companies. The profitability of sweet blood for retail drugstores and for manufacturers of pharmaceuticals, blood glucose monitors, insulin pumps, and supplies lies not only in channelling personal income, but also in securing funds from “third parties” via the health problems of specific

individuals. Governments and other insurers seek to limit expenditures and to maximize cost-effectiveness. As intensive surveillance and the consumption of pharmaceuticals (to unsweeten blood and to aid in smoking cessation, for example) may slow or prevent the onset of “complications” among people with diabetes, their future health status and future health bills remain undetermined. The predictable futures of statistically-defined populations exist in tension with the indeterminacy of the future for specific individuals, providing incentives for all concerned to spend time and money – but how much?

In his last annual report to Imasco shareholders, Shoppers Drug Mart Chair and CEO David Bloom observed that the ageing of the Canadian population favours the drugstore industry (Bloom 1999, 12). Yet, he added, these same demographic trends have also increased total health care costs, resulting in “downward pressure on prescription margins brought on by public and private efforts to reduce costs.” In other words, “good news” for manufacturers and retailers of medical technologies represents “bad news” for governments and other parties, consumers included, who foot the bills for these innovations. For consumer-patients, of course, the “bad news” encompasses the lived experience of illness and reduced future prospects.

The notion that “we” might so value human life that health care and health promotion could command, rather than compete for, money and other resources has a romantic ring. Yet if commodification is a universal human phenomenon, the commodification of human lives would appear inevitable. The commodification of human lives does not mean that persons invariably circulate as “commodities” or “gifts,” I hasten to add, but rather that they constantly undergo valuation and seem, to varying degrees, replaceable, reproducible, and amenable to improvement (Kopytoff 1986; Strathern 1996). Ethnographic research can elucidate how, not whether, human bodies undergo commodification in a given arena.

The possibility of replacing and improving human bodies over time underpins professional salaries and the marketing of myriad technologies

involved in detecting and managing sweet blood, as I outlined earlier in this thesis when distinguishing between “commodities” and “commodification” (see Chapter 3). The commodification of human bodies thus precedes and justifies the salaries of biomedical personnel and the commercial sale of biomedical technologies. The commodification of human bodies also underpins the manufacture of cigarettes. Such products hardly extend lives, for in the long run they often “give” disease, but smokers buy them – feel they need them – nonetheless. With few limits on what money can buy in contemporary Canada, medications and cigarettes may even seem interchangeable from the perspective of merchants and their accountants. Both bring people into drugstores, for example, where they might succumb to other “impulses.”

The trick of the Healthwatch® brand and related services has been to coat expenditures on disease management and prevention in a reassuring package, one that yields repeat business and a high visit-to-profit ratio. Crucially, the Healthwatch® brand portrays pharmacists as interchangeable, all equally caring and knowledgeable about internationally-accepted health products, but also conveniently accessible across Canada. The interplay between local, national, and transnational markets intersect with the needs and desires embodied by populations, one individual and one sale at a time. Sweet blood played a lead role in “repositioning” the image and practice of Shoppers Drug Mart’s retail pharmacist associates. The availability of statistical data with which to quantify the profitability of the diabetes market, including the frequency with which people with diabetes enter the pharmacy to obtain prescriptions and supplies, was instrumental in rethinking the significance of sweet blood and its management for the company.

In the late 1980s, some predicted that by the year 2000, pharmacists would become health advisors, such that “you’ll have to make an appointment and pay a fee for the consultation as you would with a physician” (Rasky 1988, 325). In fact, by the year 2000, Shoppers Drug Mart and certain competitors had “freed up” pharmacists to “give away” consultation services on the spot and by

appointment, the better to protect choice market share and profit margins. Healthwatch® services aim to “add value” to a range of purchases and, thereby, to secure customer loyalty. The development and promotion of “free” Healthwatch® services, such as diabetes education, also help justify the annual franchise fee levied on associate pharmacists. The retail pharmacist receives billing as a health professional, “free” to “share” their expertise with customers who value their help, and the mercantile dimensions of the operation – including cigarette sales in many cases – may fade into the profitable background.

Just when pharmaceuticals and other medical products change hands in return for money in pharmacies, just when they seem to most clearly comprise commodities, they may become imbued with qualities usually associated with gifts in the anthropological literature (see also Prest 2000; Yang 2000). They remain symbolically attached to their (socially-designated) origins; they express and perpetuate interdependent relationships; they index qualitative differences and social rank; and they establish and cement subject positions.

With the Healthwatch© brand, Shoppers Drug Mart has heightened the association between health and their cadre of pharmacists. The Healthwatch© brand signals that pharmacists can add value to pharmaceuticals, “nutraceuticals,” equipment, and supplies by supplying helpful information in a caring, personal manner. Such goods and services have a price, but they are also endowed with the capacity to enhance the quality of customers’ lives. The very existence of the Healthwatch© brand and its success underscores relationships of interdependence between several “subject positions,” including pharmacists, physicians, manufacturers, and customer-patients.

The information provided by pharmacists about sweet blood and other medical conditions, as well as the biomedical technologies that they sell, can serve as metonymic “offshoots” of both the treating physician and the dispensing pharmacist. Indeed, from the perspective of the patient, the information provided by the pharmacist may serve as a “second opinion” that reinforces *or* undermines confidence in the physician. Since they remain symbolically attached to health

care professionals, even while in the hands and in the very bodies of patients, biomedical technologies consumed at the behest of health care professionals do not become completely detached (alienated) from these professionals. Legally, people may only obtain commodities such as insulin from a pharmacist with a prescription from a physician. The physician, the pharmacist, or both are liable for any errors in prescribing and dispensing prescription drugs by virtue of their fiduciary responsibilities. The famed “placebo effect” signals that the consumption of prescribed medications involves ingesting the knowledge, concern, and access to a rationed pharmacopia that physicians and pharmacists embody (after van der Geest, Whyte, and Hardon 1996, who confine their remarks to physicians).

In addition to the pharmaceuticals and medical devices sold by pharmacists, cigarettes may take on the trappings that anthropologists usually reserve for gifts, to the exclusion of commodities. Ironically, given their deleterious effects on health and longevity, cigarettes also improve and “normalize” life from the perspective of regular smokers. The sale and consumption of cigarettes expresses interdependent relationships between smokers, the manufacturers, and vendors. The visitation of smoking-related health problems, such as cardiovascular disease or “mere” addiction, throws into relief the ties that bind individual smokers, cigarette manufacturers, and retailers. Following in the footsteps of epidemiological statistics that have traced the effects of tobacco consumption over time in large populations, and situating themselves in such populations, it may seem to ill smokers that cigarette manufacturers and vendors “gave” them disease. Whether sold in drugstores or not, cigarettes help define the subject positions of pharmacists and customers, physicians and patients by causing and worsening a host of health problems.

As customers become “typed” in finer and finer terms (smoker? type 2 diabetic? internet user? – and so on), terms that imbricate people with sales and with potential sales, retailers and manufacturers truly understand people simultaneously – and interchangeably – as individuals and as populations, the

essence of “governmentality” (Foucault 1991 {1978}). In the data bases currently maintained by drugstore chains, biomedical categories mingle with postal codes, annual incomes, insurance plans, birthdays, and popular perfumes. A feature article on loyalty cards powered by point-of-sale technologies recently observed:

...the data derived from increasingly sophisticated hardware and software systems are bringing the large retail chains closer to the retail spirit of the small general stores of a century ago. Once upon a time, the person behind the counter knew virtually everything about everybody who walked into the shop. And that’s really what today’s technology and information gathering is leading up to: a return to one-to-one customer intimacy.

(Menzies 2001)

The intimacy achieved through point-of-sale technologies implicates distant statistical analysts, “data miners,” rather than coming into being through direct observation and face-to-face dialogues.

Revisiting “the genealogical method” pioneered by Rivers prior to the First World War (see Kuper 1988, 161-162), this chapter underscores that the classification of people accompanies the transmission and the circulation of things, often structuring emotions. Further, “genealogical” research may reveal connections between people and things that have tended to remain invisible. In “the West,” property relations often “cut” relationships (Strathern 1996), but they may “paste” them too. Brand names such as Healthwatch®, Humalog®, Viagra®, and Player’s® connect customers, merchants, and manufacturers, while shielding certain property relationships. At the outset of this research, I did not know that Player’s© was, in effect, a Shoppers Drug Mart “house brand” during the Imasco years. When I saw *The Insider*, I did not know that each blue and white pack of Player’s© cigarettes – a familiar enough sight in this country – is “related” to the tobacco-nicotine company cast as the villain in the piece. I did not set out to write about the pharmacy business, and certainly not the tobacco-nicotine industry. The twists and turns of field research bent on uncovering how

sweet blood achieved greater recognition as a social-*qua*-health problem pointed to genealogies that include such “players.”

## **9. Tackling Diabetes in a World that Sweetens Blood: Anthropology, Biomedicine, Liberalism, and Capitalism**

Unlike AIDS, diabetes is not an affliction born of the twentieth century. It has been recognized in the Western medical tradition for centuries, although its definition has not remained pat. The diagnostic criteria currently in use depend on the abilities, developed over the past 150 years, to measure the amount of glucose in a sample of blood and to study populations using statistics. While diabetes did not suddenly appear at the close of the twentieth century, sweet blood gained heightened social significance at this time. Its rising profile caught my attention, and suggested a fruitful line of inquiry for this research project. To its core, this thesis concerns how “we” know our bodies and the bodies of others.

Confronted with the spread of AIDS, anthropologists paid close attention to how individual biographies interweave with historical processes enacted over vast geographies. The problem of sweet blood in Canada, particularly as it affects Aboriginal people, resonates with the political economy approach to the distribution of disease and suffering that Farmer influentially brought to the study of AIDS and related ills in Haiti (Farmer 1992). Yet one of the most striking dimensions of the problem of sweet blood in contemporary Canada is that it is gaining recognition apace, even as I compose this sentence.

Farmer fights fire with fire, highlighting racism against Haitians in the generation of statistical knowledge about AIDS by sleuthing out how American vectors of infection and foreign policy contributed to the epidemic in Haiti. While Farmer contrasts and combines ethnography (the documentation and interpretation of experience) epidemiology (the collection and interpretation of statistics about disease), history, and political economy, I regard statistical

knowledge first and foremost as social facts whose degree of social salience warrants explication.

The present ethnography *of* epidemiology has examined the history, generation, dissemination, and interpretation of a class of symbols – statistics – in terms of core concerns in the political economy tradition: production, appropriation, and exchange. This task has involved unpacking biomedical knowledge about sweet blood, which spans the distant past, the “current physiological dogma,” and the frontiers of genetic research; accounting for clinical, public health, and science policies recently adopted in Canada; scrutinizing coverage of the problem of sweet blood in the mass media, both through advertising and by journalists; and investigating the marketing of diabetes-related products and services.

Throughout this thesis, I have repatriated concepts and theories originally developed to describe “non-Western” societies to “Western” readers. The fruitful interplay of theory and empirical research displayed in this thesis (as opposed to off-the-cuff reflections privileging the “native point of view” held by ethnographers regarding their own society) serves as a reminder that “the West” is ripe for excavation. Ethnographers historically regarded “marginal” peoples the world over – from the Trobriand Islands to the slums of Chicago (Cappetti 1993) – as alternative versions of themselves, and in these comparisons, they held “the West” steady as a point of reference. This thesis turns the proverbial mirror around to account for how “Western” institutions actually operate.

I have shed new light on how “our” economic system, political system, and health care system intertwine through the medium of human bodies, highlighting some unexamined assumptions about statistics, disease, kinship, commodification, and money in “the West.” In these regards, the theoretical and practical significance of this thesis extends well beyond the problem of sweet blood in Canada. More specifically, I have shown that, through the generation and application of statistics, biomedical practices establish “blood relations” among human beings who are strangers to one another and between human beings and

“lower” nonhuman beings, while also battering down likeness among immediate blood relatives. In such statistics, money routinely serves as standard unit of measure, one that evokes and channels emotion by purporting to approximate value (of various orders) vested in human bodies. Through such processes, human bodies undergo commodification without being bought, sold, or bartered outright.

The suggestion that “we” could and should design a health care system – or a society, or a world-view for that matter – that excluded the commodification of people is a wish that many hold dear. When anthropologists find that human bodies undergo commodification, the tinge of evil that clung to capitalism and its commodities in the history of the discipline clearly remains in evidence (Bloch and Parry 1989; Miller 1995 for discussion). “Body fragmentation and commodification are troubling themes in anthropology,” begins a recent review article, whose “myriad examples offer compelling critiques of dehumanizing processes” (Sharp 2000, 287, 316). Yet if people everywhere commodify themselves and fellow travellers, different regimes surely vary greatly in the form and the degree of inequality. Ethnographic research can play a crucial role in teasing out just how power articulates with human bodies. This thesis underscores that quantification and other modalities for commodifying human bodies and their parts do not spell, *ipso facto*, dehumanization. Indeed, statistics are routinely deployed to valorize human life; the rub is that they readily permit evaluative comparisons and lend themselves to plans that may or may not benefit or accord with the express wishes of the persons represented.

### **GOOD RIDDANCE**

This thesis has shown that the problem of sweet blood in Canada has gained significance not only because it is known to strike “the colonized” (Aboriginal people), but *also* “the innocent” (children), “the comfortable middle” (baby-boomers), and those living out their “golden years” (elderly). “Society” has been fingered as lacking the technical capacity – and perhaps the moral fibre as well – to rid itself altogether of the problem of sweet blood. In the case of type 2

diabetes, a “lifestyle” that is widely promoted and enacted has been identified as the progenitor of disease on a massive scale. Technologies and techniques are in place, however, to unsweeten blood once the problem has set in. The money that flows to sop up the problem transforms from blighted expenditure into the pretty penny of profit as it changes hands.

Research on diabetes, actions that aim to prevent or manage diabetes, and the diagnostic criteria themselves are all predicated upon supposing that people embody greater health and better prospects without sweet blood flowing through their veins. The sweetening of blood is viewed as an unwelcome development that can and should be stopped, not as an essential or inevitable feature of certain persons. This emphasis on sculpting the body extends to genetic understandings of diabetes. Genetic research into diabetes ties the definition of pathology firmly to physiology – in contrast with my original expectations, derived from the social science literature. In clinical practice, however, health professionals often greet the detection of sickly sweet blood with fatalism, regarding the patient’s body as a ticking time bomb (see also Loewe and Freeman 2000). The researchers featured in this thesis therefore marshal evidence showing that sweet blood will yield to intensive control. They exhort clinicians to regard the management of diabetes as an enterprise worthy of their attention and that of their patients. In doing so, they highlight physiological and genetic characteristics that may reinforce and even redefine social identities. These include “type 1 diabetes” as compared with “type 2 diabetes.” In light of the current technical inability to prevent type 1 diabetes from occurring, and the intractability of a “lifestyle” predisposing to type 2 diabetes, many people currently hope that biomedical research will provide deliverance.

Nourished by information provided by researchers and lobby groups, government officials and journalists have expounded upon the global financial impact of the disease and stressed that sweet blood and associated “complications” may be prevented from taking hold in the first place. Public and private insurers alike would prefer to reduce diabetes-related claims. Private

insurers routinely refuse coverage to people with diabetes, but (federally-supported) provincial health plans in Canada must offer insurance to all, regardless of health status. Both public and private insurance plans restrict coverage for such things as pharmaceuticals, equipment, dietary advice, and supplies. People with diabetes must pay out of pocket for such goods and services, or go without. Tabulating diabetes-related expenditures and “lost” productivity helps convey the sheer magnitude of the problem, which helps justify spending on health promotion and research. Meanwhile, businesses such as pharmacies and pharmaceutical companies have increasingly identified the unrelenting financial impact of diabetes as a boon.

### **POSSESSED OF KNOWLEDGE**

Over the past fifteen years, anthropologists have paid increasing attention to how the human body mediates self and society. In focusing on embodiment, anthropologists have joined sociologists and philosophers in questioning the notion that knowledge derives from autonomous cognition, as though “the mind,” effectively removed from the world, were universally distinct from the worldly body (Lock 1993a for review). Many have turned for inspiration to phenomenology, which highlights that persons both *have* and *are* bodies. This insight grounds the analytic distinction between illness and disease in the anthropology of medical systems. “Illness” carves out a place for the subjective experience of the afflicted person, while “disease” refers to objective abnormalities exhibited by the body (Eisenberg 1977; Kleinman 1980; Young 1982).

Ironically, through the popularization of the disease-illness distinction, contrasting illness with disease “has come to distinguish the subjective aspects of patient belief from the supposedly objective perspective of the treating physician,” such that “while patients have *experiences* worth eliciting, physicians have clinical *reasons*” (Loewe and Freeman 2000, 381). In other words, the creation, elaboration, interpretation, and use of biomedical knowledge by

professionals seem oddly disembodied. It is as though the sentiment-laden physical body did not intrude in biomedical research and clinical practice. Yet a pioneering ethnography of biomedical research highlighted that scientific knowledge about disease engages diverse emotions that, in a recursive manner, fuel thinking, feeling, and action (Fleck 1979{1935}). In addition, ethnographic research on the experience of managing type 2 diabetes for patients as compared with physicians has found that the disease may provoke strong emotions in both groups (Ferzacca 2000; Loewe and Freeman 2000). Physicians often express frustration with the lack of control over sweet blood exhibited by patients, and they find it difficult to deal systematically with several “complications” and treatment issues, which often “present” simultaneously. For them, statistically-grounded fears of damage to internal organs, especially the heart and kidney, loom large. Meanwhile, the diabetics themselves focus more on the day-to-day grind, mastery of their bodies if not the disease, and the threat of such visible manifestations as blindness and limb amputations.

My research on the generation and dissemination of “clinical reasons” for controlling sweet blood largely confirms these observations about biomedical research and the treatment of diabetes. I found that the embodied possession of awareness of the impact of sweet blood triggers diverse emotions and associations among people with *and* without diabetes. Treating physicians, researchers, politicians, bureaucrats, journalists, and businessmen – all in their respective professional capacities – understand sweet blood and its effects by way of statistically-studded narratives but also via salient memories (prototypes), typical cases, and routinized templates for action. To achieve recognition for the gravity of sweet blood, it has proved important to emphasize that diabetes comprises multiple problems that *appear* to be separate because they arise in different sequences and to different degrees, if at all, in members of the affected population (cf. Fleck 1979{1935} on syphilis). Statistics, the experience of witnessing, and tales of dread glue sweet blood together with kidney damage, poor circulation resulting in limb amputation, heart disease, sexual dysfunction in men,

“complicated” pregnancies in women, blindness, blank cheques for health care expenditures, and “lost” productivity, among other ills (cf. Young 1995, 6 on post-traumatic stress disorder).

Among people diagnosed with diabetes, the visceral experience of sweet blood routinely interlaces with statistical associations. Given that contemporary anthropologists often contrast the lived experience of suffering with “impersonal” calculations, it bears underscoring that people with sweet blood comprehend and manage their condition via statistical associations in many respects, even if they (like clinicians) do not always reason in terms of probabilities.

The very definition of diabetes as a disease pivots upon a quantitative threshold, established with reference to longitudinal research on statistically-fashioned populations. Typically, people with diabetes learn to frame headaches, fatigue, and other bodily states in terms of the sweetness of their blood *after* diagnosis. They may not even report feeling sick prior to diagnosis. Diabetes education classes promote the internalization of facts and figures – “general knowledge” – about the disease, but with reference to personal experience (see also Cohn 1997). Professionals and diabetic participants alike in the diabetes education classes that I attended compared knowledge *about* diabetes with visceral knowledge of abnormally high and abnormally low blood sugar, underlining that they considered individual experience and biomedical expertise to be distinct ways of knowing that index one another. Life with dialysis and death by heart failure were volunteered as potential long-term consequences of sweetened blood by participants whose close relatives with diabetes had developed these conditions. Participants spontaneously described the regime of self-surveillance as a “complication,” thereby transposing the biomedical term for long-term organ damage to the daily routine designed to prevent such damage.

### **TO HAVE AND TO HOLD**

Statistical values used to measure and compare bodies flatten the past, present, and future into a single, powerful dimension. Glucose levels in human

bodies may index several things simultaneously due to indeterminacy in the exact nature, causes, and timing of consequences arising from the sustained presence of sweet blood in a given body, as well as diverse positions (“interests”) in relation to diabetic bodies. Measuring the production and absorption of glucose within the human body may mark the worth of that physical body and its future, the relative strength of embodied will power, and the quality of the enfolding society.

Statistical knowledge about the habits of the populace and about the availability of skilled health professionals, food, and medications has both symbolic and material import. As synecdoches that compress and evoke value, biomedical statistics recognize individual persons as occupants of their bodies, while also engendering many other possessive relationships. References to “my medications,” “my doctor,” and “my diabetes” mirror references to “our customers,” “your patients,” and “their data.”

Biomedical statistics bespeak human prowess, but also frailty. The ability to link bodies synecdochally with numbers gives rise to the capacity to envision and design a future. The bridge that statistics provide from the past through the present to an impending future yield projections ranging from “best case” to “worst case” scenarios. It seems a clever thing to follow the markers indicating the most value for money, “within reason.” Global, national, provincial, local, and personal modalities of signification simultaneously enter the equation. They permit some semblance of “being there,” of an intimate knowledge of the inside of bodies and of the contours of future populations (cf. Povinelli 1993, 237-241).

In light of what statistical technologies enable, the dual character of human bodies – as both the essence of human beings and their first, most intimate possession – elaborated in phenomenological inquiries carries heightened significance. Phenomenology takes an exact, attentive inspection of mental and other bodily processes as its point of departure. It situates the self – nested within a body – within the world and denies any abstraction from this embodied, worldly self (Csordas 1994). For ethnographers, inner inspection entails some ability to experience “a bodily awareness of the other within oneself,” given their concern

with elucidating how people interact with one another and with the world around them (Jackson 1989, 130). Hence, phenomenological inquiry segues into the interpretation of human action, utterances, products, and institutions – that is, to hermeneutic skill and theory. Phenomenological accounts of illness tend to invoke the self as a universal concept whose realization varies according to the individual and the ambient culture, giving rise to the capacity to interpret if not experience fully the suffering of others.

This study underscores the importance of statistics for generating knowledge and framing experience under biomedicine, liberalism, and capitalism. Through conversations and in texts steeped with calculations, health care providers, researchers, government officials, and journalists (not to mention anthropologists) chart how persons riven with sweet blood live in their bodies and how this sorry state of affairs came to be. Such encounters both describe and help shape relationships among people and things, including how people perceive and experience their very bodies (Foucault 1971 {1970}). “The” self is therefore not alone in knowing or even experiencing “the” body.

The distinction between persons and bodies, which gives rise to imagining an earthly utopia where sweetened blood would not intrude, underpins biomedicine by leaning on liberalism. Notably, the notion that lives can be “saved” (prolonged) pivots both on recognizing persons and bodies as distinct entities that entwine. More precisely, the body appears to seat the liberal subject. While bodies may not qualify as the “property” of the individual inhabitant in the judicial sense (they cannot be lawfully sold, for example), liberalism understands persons to exercise freedom and inalienable rights through the medium of their bodies. Under liberalism, the person occupies a privileged position with respect to knowing and reporting on the self and the body. This authentic knowledge, however, routinely undergoes inspection, evaluation, and codification in institutions. In these regards, the people who occupy biomedical and other institutions possess bodies that extend beyond themselves and their own skins, as

the analysis of opinion polling and other research modalities in this thesis has underscored.

Sovereign liberal subjects encased in pliant bodies stand revealed as historical figments, rather than patent universal truths, in recent anthropological writings about the body. Nevertheless, the interpretative turn in anthropology combined with phenomenological inquiries into embodiment have reinforced the notion that bounded bodies spring from nature, in which cultural selves take root and grow. Yet statistics synecdochally present a situation in which people belong to far-flung populations, such that power simultaneously operates through the manipulation of statistics and beneath the skin of its subjects (Foucault 1994 {1978}). To have a body, under these circumstances, entails visceral and virtual dimensions of existence. Those in possession of biomedical and demographic statistics have in their grasp a material trace, a dimension of the bodies of others. Liberalism portrays subjects in the possession of statistics as harbouring knowledge about the persons or things signified, but as not possessing the signified itself. Phenomenology has tended to reinforce liberal self/other dualism, but leaves scope for considering how “the other” becomes part and parcel of experience, blurring the boundaries of “the” body (Boddy 1994).

In putting aside conventional understandings of property to focus on the politics of possession as they interlace with human bodies marked by sweet blood, the archeological and ethnographic record supply helpful conceptual tools. The human body and statistical representations thereof fulfil the broad criteria that archeologists use to discern property relations across human history, while ethnographic research on gift exchange highlights that possession need not imply license to use, transmit, and dispose at will. Through synecdochal relationships bridging people and things, gifts still belong to the giver in many respects. To the extent that knowledge is unevenly distributed within and across all societies (Keesing 1987), knowledge represents a kind of possession whose value depends on selective enactment, which may involve the classification, marking, and distribution of materials. People may thus gain in knowledge and in value by

claiming, acquiring, transforming, and transmitting certain things (after Appadurai 1986).

While all human societies restrict the use, allocation, and transfer of certain things, these restrictions and the things in question vary enormously. It has been suggested that a pan-human concept of property might boil down to “keep your cotton pickin’ hands off my [whatever]” (Neale 1998). Archeologists interested in property relations, whose research almost always proceeds without the benefits of written and oral sources, infer agency, power, and social significance from the location of bodies and from the fact of possession. They examine the available physical evidence for signs of improvement and movement of objects, the patterning of conflict (raiding and violence, in particular), the patterned distribution of people and associated objects across the landscape, and the marking of both landscapes and moveable objects (Earle 2000 for review).

Burial mounds and markers in the archeological record suggest strong associations between certain objects and individuals in many societies. Ethnographic research, meanwhile, has found that mortuary ceremonies and associated objects commemorating the deceased individual also underscore the breadth and depth of kinship, which is often understood to extend beyond the grave and to span future generations. For example, the Trobriand practice of meting out the worth of deceased women as well as other members of the group by preparing, counting, assembling, exchanging, and accumulating banana leaves recognizes the perishability of human beings, their relative significance, and the continuity of their society (Weiner 1976). This thesis suggests that such observations apply to human bodies under liberalism and capitalism, and more specifically, through biomedicine.

Human bodies constitute “cultural objects,” ones whose improvement and movement remain under the control of the inhabitants (persons), according to liberalism. Human beings are also subject to desires that the purchase of commodities might satisfy and that health professionals, governments, and private enterprise may wilfully stimulate.

Statistics created to represent human bodies, including health status data and monetary projections, also constitute “cultural objects” that may be improved and moved. Indeed, the collection and manipulation of numbers – in archeological terms, “markings” – may presage the improvement and movement of human bodies. In this sense, human bodies belong to their inhabitants in liberal democracies, but beholders of statistical representations of these bodies also possess a piece of them. These “markings” may be so wrought as to transfigure how persons experience their bodies, and in fact, how long they experience embodiment (that is, the length of their lives). Biomedical statistics routinely negotiate fundamental differences between people’s lives and bodies by extending the personal, idiosyncratic import accorded human life to other people’s bodies on the basis of an underlying equivalence, derived from liberalism: all human beings have equal rights. In this way, statistics valorize the self by, paradoxically, rendering persons as interchangeable with each other, yet differentiable by the extent to which they embody health and promise. The statistical rendering of human lives thus marshals three kinds of value – idiosyncratic, underlying equivalence, and the accommodation of fundamental differences – that have been discerned separately and even opposed in the ethnographic literature (Thomas 1991, 30-32).

The dual geographic and temporal patterning of human beings and statistical representations thereof in medical charts, tables, and graphs do not themselves define property rights, but they do associate resources with groups. Only certain people may possess statistics in the raw, but “anybody” may possess once “cooked” (anonymized and published). Persons may collect and analyze statistics about themselves, and they routinely do, recording and tallying the number of calories that they consume throughout the day, for example. Persons with diabetes are urged to quantify food consumption – with special attention to “counting carbs [carbohydrates]” – as well as the sweetness of their blood. Just who may amass and examine statistics about others is subject to regulation and constitutes a contentious issue in certain quarters.

Citing privacy concerns, government agencies that collect, analyze, and publish statistics “anonymize” the data to shield the identity of individuals. As highlighted in this thesis, in relation to the Canada-wide diabetes surveillance system currently under construction, many citizens (including researchers) feel concern over who will have access to “their” data. First Nations in Canada contest under the OCA (ownership, control, and access) banner the control symbolized and exercised over them through the collection and analysis of statistics.

Health care professionals have privileged access to the bodies of their patients, to the point that the medical chart does not really belong to the person described therein. Physicians routinely convey the results of fasting plasma glucose, glycated hemoglobin, and many other tests to their patients in person or by telephone; patients who wish to examine their medical charts first-hand must petition to do so in a protracted process. Similar to gifts in Melanesia, blood given for the purposes of treatment (as opposed to being donated for use by someone else) returns to its source in another form, here as knowledge that brings certain powers.

The right to collect and analyze statistics about one’s self extends to fictive persons: corporations. Currently, computers mediate purchases (through credit cards and the collection of point-of-sale data, for instance) and, increasingly, data banks undergo linkages that enable analysts to track and classify consumption patterns. Such linkages routinely depend upon decomposing populations into individuals with unique identifiers that can be matched. These capacities have given rise to a rash of privacy concerns, which signal the extent to which human action leaves behind paper and digital “after lives” in the contemporary period. Since statistics may be reproduced *ad infinitum*, statistical representations of human bodies may fall into the possession of many people and enter manifold circuits of exchange.

## THE EYE OF THE BEHOLDER

Many eyes behold sweet blood coursing through the veins of individuals and populations, wreaking havoc and fraying lives. Through the medium of this thesis, the author and the reader have joined the ranks of these seers. Rather than painting a clutch of human beings with sweet blood into a large canvas – a well-trodden path that has yielded many exemplary studies, some of which I have cited with approval – this thesis has examined how diabetes came into renewed focus across various fields of vision.

In Canada, people suffer with sweet blood in relation to institutions that assess how much they suffer, what they really need, the extent to which their “lifestyle” predisposes them to sweet blood, and how worthy they are of attention. This thesis has shown such processes to be thoroughly political and economic and cultural, questioning the very distinctions between these terms. It highlights some ways in which anthropology participates in a political economy through which suffering becomes visible as such and (yet?) remains, laying open processes through which people – “experts” and “lay” – inspect themselves and evaluate others. By implication, it asks why some ways of experiencing the world regularly surface as seemly topics for ethnographic enquiry and for media exposé, to the exclusion of others. A hankering lingers for downtrodden and down-on-their-luck figures, which “flavours of the month” periodically dislodge into abeyance. And yet, upon close inspection, symbolism so pervades “normalcy” that it *seems* reduced to mundane matters of fact. Perhaps the practice of rendering human beings as points on graphs, where vistas on life run into disease and death, appears most natural of all.

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