Examining Public Health System Responses to the Chronic Diseases of HIV/AIDS and Diabetes: Experiences from Mexico and Brazil

By

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A dissertation submitted in partial satisfaction of the requirements for the degree of Doctor of Public Health in the Graduate Division of the University of California, Berkeley

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Abstract

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Background: Health systems around the world have historically been oriented toward acute care, but over the past century chronic diseases have become the leading causes of death globally. It has been estimated that 80% of the burden of chronic diseases occur in low and middle-income countries. However, there is a gap in the scientific literature regarding how these countries are addressing their burgeoning chronic disease burden, how chronic disease management models inform public health system organizations, and how health sector reform efforts intersect with chronic disease and its management. Purpose: The current work aims to address this specific gap by examining the public health system responses to HIV/AIDS and type 2 diabetes in the middle-income countries of Mexico and Brazil. Methodology: After reviewing existing models of chronic disease care and health systems, a new model was developed to examine the public health system responses to chronic diseases. The model was used to guide a literature review on health sector reform, HIV/AIDS, and diabetes in Mexico and Brazil. Quantitative and qualitative secondary data was supplemented by information gathered through qualitative interviews with experts in both countries from federal government, state/municipal government, non-governmental organizations, and academia working in the area of HIV/AIDS or diabetes. Data were analyzed according to the proposed model, and case studies were developed. Findings: The proposed model examines financing and expenditures, policy (including prevention), service delivery, medical products, self-management support, workforce, and health information technology. The study revealed the need to incorporate community involvement into the model and a number of additional indicators. A centralized procurement and health information system to monitor and control dispensation of medications, similar to Brazil’s system for antiretroviral medications, would likely reduce long term costs and improve patient care in Mexico and elsewhere. Utilization of a primary care approach using multidisciplinary health teams may be the best mechanism to improve overall processes for chronic care and health outcomes. A civil rights, social justice approach employed by the citizenry to engage governments was critical in Brazil and Mexico to garner support for services and resources to combat HIV/AIDS and stimulate health sector reform.
For R, for inspiring me to go west
Acknowledgements

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The UC-Berkeley DrPH program was the right thing at the right time. I am grateful for that gift. Things fell into place so perfectly that I know I need to “pay it forward” by taking all I have gained and making a difference. Chronic diseases will touch everyone we know and love, and we need a health care system, not a sick care system, to prevent and treat them.

“In the midst of difficulty lies opportunity.” – Albert Einstein.
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Introduction
Health systems around the world have historically been oriented toward acute care, largely responding to an infectious disease burden, particularly in low and middle-income (LMI) countries [1-4]. However, over the past century, mortality attributable to infectious disease has declined significantly, and chronic diseases have become the leading cause of death globally [5, 6]. The prominence of chronic disease is not limited to high-income countries. LMI countries already face a significant chronic disease burden that is expected to increase over the next few decades. In fact, it has been estimated that 80% of the burden of chronic disease deaths occur in LMI countries [6]. Consequently, these countries face a “double burden” of disease, posing a significant challenge to their health systems. These chronic diseases cannot be managed through a conventional acute care approach, but rather require a more integrated, complex and sustained response from the health system.

A country’s ability to respond to disease with its health system is often driven by socioeconomic factors. Low-income countries are frequently dependent on external sources of aid to build or reform their health care systems. High-income countries often invest their own significant resources in their health care systems. Middle-income countries (MICs) are somewhere in between, frequently with some level of external financial support, but largely dependent on their own developing economies to sustain their health systems. These countries are often strained by huge socioeconomic and health disparities. Nonetheless, the experiences of MICs in health sector reform can inform policy in countries at all income levels. How, then, can MICs shape their public health systems to most effectively address their burgeoning chronic disease burden?

HIV/AIDS and type 2 diabetes are two preventable diseases that represent a significant portion of the chronic disease burden around the world and in many MICs. There are an estimated 33 million people living with HIV/AIDS and 246 million people living with diabetes [7, 8]. The risk factors for type 2 diabetes and HIV are behavioral in nature and largely preventable; HIV/AIDS infection is largely driven through sexual transmission, and diabetes is related to overweight and obesity. The global per capita expenditure on HIV/AIDS far exceeds that of diabetes, although overall expenditure on diabetes is greater. This is particularly true in LMI countries, which bear the majority of the disease burden. It is worth exploring the health system responses to these diseases in tandem because their overall management is similar. These diseases, marked by episodic acuity, require diagnosis, patient self-monitoring, ongoing medical monitoring, and treatment that will accrue significant expenditures over the patient’s lifetime.

Mexico and Brazil are middle-income countries that have similar demographic characteristics, have recently undergone significant reform to their public health systems, and have similar epidemiological profiles, including a high burden of chronic disease. Specifically, they have the greatest number of people living with HIV and type 2 diabetes mellitus in Latin America. Both have guaranteed universal access to anti-retroviral therapy (ART) for people living with HIV, although Brazil has come closer to realizing this goal. Both are attempting to fight growing rates of diabetes, but public awareness and government led interventions seem stronger in Mexico. The implications of these diseases, including rising costs of care and the government’s ability to pay for them, coupled with the population’s expectations for fairness and responsiveness, may shape health sector reform in these countries. The purpose of this current work is to explore how the public health systems in Mexico and Brazil have responded to HIV/AIDS and to diabetes and draw lessons and policy recommendations from these experiences.
Background
It has been well documented in the literature that chronic disease has been steadily increasing throughout the past century. Hoffman et al noted that health statisticians found that chronic diseases were replacing infectious disease as the dominant health care challenge in the United States as early as the 1920s [9]. The World Health Organization (WHO) estimated that chronic disease accounted for 60% (35 million) of the 58 million deaths worldwide in 2005, double the estimate for all infectious diseases [6]. This figure does not include the 2.8 million deaths due to HIV/AIDS or the 1.6 million due to tuberculosis, which can be considered chronic diseases where treatment is available. Contrary to popular belief that chronic diseases are the exclusive domain of the wealthy, WHO estimates that eighty percent of the deaths due to chronic disease will occur in low and middle-income countries [6].

The trend of shifting from a heavy burden of infectious disease to one of chronic disease is described as the epidemiological transition, a term first coined in 1971 [10]. This “epidemiological transition” in countries is driven by three major sets of determinants: ecobiologic; socioeconomic, political and cultural; and medical and public health interventions [11]. However, Yach et al point out that the transition has not occurred smoothly in the developing world. As Frenk et al noted, middle-income countries suffer from a polarized and protracted transition, resulting in the coexistence of pre-and post-transitional diseases [12]. This coexistence is frequently referred to as a “double burden” of disease, and poses a significant challenge to health systems.

Chronic Disease: Definition
Definitions of chronic disease vary, although most experts define chronic disease as being characterized by a long duration, slow progression, and unlikelihood of a cure [11, 13-15]. Some use the term to focus on non-communicable diseases, emphasizing the non-contagious origin. However, as McQueen et al point out, it is difficult to provide an exact separation of infectious from chronic diseases, as many infectious diseases have chronic sequelae (2001). Dowrick et al have stated that “Chronic diseases are prolonged, do not resolve spontaneously, and are rarely cured” [15]. They and other experts have come to recognize HIV/AIDS, tuberculosis, and certain types of cancer as chronic diseases, although the latter two can be cured. However, it is important to note that HIV/AIDS can be considered a chronic disease only in those environments where effective treatment is available. This work will consider HIV/AIDS to be a chronic disease, as the countries that will be discussed have such treatment available.

Significance of Chronic Disease Burden
The burden of chronic disease is significant for a number of reasons. First, it is clearly growing on a global scale, and its ramifications are important. The World Health Organization (WHO) estimated that chronic disease accounted for 60% (35 million) of the 58 million deaths worldwide in 2005, double the estimate for all infectious diseases [6]. In the United States alone, it was estimated that 133 million people, or 43.7 % of the population, had at least one chronic condition in 2005 [16, 17]. Of these, approximately 11% of the population was estimated to have two chronic conditions, while about 13% had three or more (multiple) chronic conditions. The percent of people reporting three or more chronic conditions in 2005 over 1996 grew more than groups reporting only one or two conditions, particularly those in the oldest age groups [17].
In addition to being a leading cause of death, chronic disease has major adverse effects on the quality and length of life of affected individuals [18]. These effects do not stop with the individual, but create a ripple effect. The individual may no longer be able to work at full capacity or at all, which could have dramatic emotional and economic implications for his/her family. Foregone income due to illness is not limited to the individual, but also to his/her caregivers and surrounding community.

Finally, chronic disease directly impacts families, communities, and nations through its impact on the health care system. It has been found that people with chronic health problems are more likely to utilize health care, particularly when they have multiple health problems [19]. This increased demand can impact access to care, as well as cost. One group of researchers in the United States developed a model to determine the lifetime costs of complications resulting from type 2 diabetes and found that over the course of 30 years costs could range as high as $47,240 per patient, with macrovascular disease and neuropathy accounting for the greatest cost components [20]. Chronic diseases cannot be successfully managed through a conventional acute care approach, but rather require a more integrated, complex and sustained response from the health system [19, 21-23]. Perhaps Nolte and McKee best describe the necessary response:

“…[chronic diseases] require a complex response over an extended period of time that involves coordinated inputs from a wide range of health professionals and access to essential medicines and monitoring systems, all of which need to be optimally embedded within a system that promotes patient empowerment.” [19].

This type of care comes with a steep price tag, although no single global estimate has been determined for the cost of health care for chronic disease worldwide. Evidence from several countries, across the income spectrum, supports this claim. For example, in the United States, it has been estimated that more than 75 percent of the approximately $2 trillion spent each year on health care is associated with the treatment of patients with one or more chronic diseases [24]. In Mexico, for example, it was recently found that the financial requirements for ambulatory and hospital care for diabetes and hypertension will amount to 9.5% of the total budget for the uninsured population and 13.5% for the insured population, and this does not include out of pocket expenses for the patient [25, 26]. Furthermore, in China, it was estimated that diet-related chronic diseases, including cancer, coronary heart disease, stroke, hypertension and diabetes, accounted for nearly 23% of health care costs and contributed to lost productivity [27].

The reasons behind the increase in the global burden of chronic disease are complex and multidimensional. At the macro level, demographic changes such as the aging of the population, urbanization, economic development and globalization have all been identified as factors related to the increase [11]. At the individual level, diet and physical activity, unsafe sexual activity, environmental risks, and tobacco, are among the leading causes of chronic disease [11, 28].

Global Response to Chronic Disease Burden

Many LMI countries simply do not have sufficient national funding to address their disease burdens and are dependent upon international assistance in health. Despite the massive upsurge in the prevalence of chronic disease, donor funding for health to low and middle-income countries appears low, although because of dedicated disease funding, exact numbers are difficult to calculate. Certainly there is little explicit recognition within development circles of the need to address chronic diseases within a health delivery system, despite data from the
Global Burden of Disease study discussed below. Funding for HIV/AIDS, which is often not put under the umbrella of chronic disease, is relatively high.

Some have estimated that of official overseas development aid (ODA) for health only 0.1% is allocated for chronic disease, excluding HIV/AIDS [11]. A 2007 study on donor funding for health in LMI countries for 2001-2005 did not even have chronic disease listed as a funding category [29]. Actual expenditure on chronic disease may be higher, since chronic disease care may fall under other higher-funded categories.

For example, in the Kates study, elements of chronic disease control might have been minimally provided for under the categories of basic health care and basic health infrastructure based on their definition. Nonetheless, it is impossible to determine precisely how much funding for chronic disease falls in those categories. Kates reported that international donor assistance for health rose from $4.1 billion in 2001 to $9.7 billion in 2005, and funding for infectious disease control rose (excluding HIV/AIDS) from $0.5 billion to $1.6 billion. Over the same period, funding for STD and HIV/AIDS control increased from $1 billion to $2.6 billion. Similarly, Shiffman found that in 2005, donor funding for HIV/AIDS accounted for 23.5% of all health & population funding, and infectious disease control accounted for another 25.6% of all funding [30]. Regardless, the level of funding for chronic diseases relative to the burden of disease is extraordinarily low compared to the level of funding for infectious diseases.

Leading Chronic Diseases
The landmark WHO Global Burden of Disease (GBD) project has been critical in demonstrating the role of chronic disease in global mortality. The most recent data describing the leading causes of death and disease burden were published in 2004 as part of the World Health Report 2004. Data revealed that the leading causes of death worldwide and across all income levels were chronic diseases. These included cardiovascular disease (principally ischaemic heart disease and stroke/cerebrovascular disease), various cancers (principally trachea/bronchus/lung cancers), and chronic obstructive pulmonary disease (COPD).

Diabetes mellitus was ranked 12th globally in 2002. This is almost exclusively attributable to type 2 diabetes, which will be the focus of the current work. Type 2 diabetes comprises between 85% and 95% of all diabetes in high-income countries and an even greater proportion in low and middle-income countries [7]. HIV/AIDS was consistently ranked within the leading 10 causes in LMI countries, as a whole. Others have furthered this work and developed projections for 2030, which indicate that chronic diseases will continue to dominate the global disease burden [31]. The diabetes burden will grow and the disease will rank 7th globally as a cause of death; HIV/AIDS will rank as 3rd leading cause of death. This projection does not take into account the recent downward revision by UNAIDS to global prevalence rates. Many have criticized the previous HIV prevalence rates and projections to be overstated, due to poor data utilization and modeling [32]. Therefore, this estimate may be high, but HIV undoubtedly will remain among the leading causes of death. Similarly, diabetes mellitus was ranked 20th in 2002, but is projected to rise to 11th place by 2030. Diabetes may be underestimated as a cause of death due to frequent comorbidity with other leading causes of death, particularly cardiovascular disease.

As previously mentioned, HIV/AIDS is not always considered a chronic disease. It is an infectious disease that can kill quickly without timely and appropriate treatment. In the early
days of the epidemic, people infected were not often diagnosed until they were extremely sick. Once diagnosed with HIV, treatment was frequently inaccessible, and people died within a short span of time due to opportunistic infections or AIDS. Consequently, in certain parts of the world, huge AIDS wards were opened in hospitals. This is one example of a health system adaptation to the disease.

However, the development of powerful antiretroviral therapy (ART) and effective distribution of the treatment has basically erased this paradigm in all but the most resource poor environments. Now, people living with HIV/AIDS (PLWHA) can live long, relatively healthy lives, if they receive ART, have good continuous monitoring to determine if drug therapies need to be adjusted, and minimize other risky behaviors that may compromise their health (e.g. poor diet, smoking, irresponsible sexual behavior, etc). Consequently, HIV/AIDS has transformed into a chronic disease that is marked by periods of acuity, when the virus mutates, the person develops an opportunistic infection, etc. Consequently, AIDS wards in hospitals basically disappeared in the United States and other environments where the course of the disease changed due to access to testing, treatment and ongoing care. Where this is unavailable, such as many resource poor environments in sub-Saharan Africa, the AIDS wards, indeed entire AIDS hospitals, remain open. For the fortunate, the “acute disease” became a chronic disease, affording people a second chance on life. Now these patients required a chronic care approach: monitoring, access to their medications, counseling, etc. Health systems again adapted.

**Why focus on HIV/AIDS and Type 2 Diabetes:**
There are four reasons why the current study focuses on HIV/AIDS and Type 2 Diabetes (further referred to as “diabetes” unless otherwise indicated): 1) significant disease burden, 2) preventable behavioral risk factors, 3) high costs/expenditures to health systems, and 4) commonalities in management of the disease.

**1) Disease burden**
HIV/AIDS and diabetes are diseases that represent a significant portion of the disease burden around the world and in many low and middle-income countries. While mortality from these diseases was described above, additional morbidity evidence supports further study of these diseases, including prevalence. It was estimated that in 2007, approximately 246 million adults (age 20-79), 6% of the world’s population, were living with diabetes [7]. Some 80 percent (196.8 million) of these lived in low- and middle-income countries. The global number was expected to grow to 380 million by 2025, or 7.3% prevalence.

In comparison, in 2007, an estimated 33 million people or approximately 0.8% of the adult population between the ages of 15-49 years were living with HIV/AIDS worldwide [8, 33]. Ninety-five percent of all people with HIV are estimated to live in low- and middle-income countries. The global 2007 estimate represents a 16% reduction from the 2006 estimate of 39.5 million, attributed to a significant correction of estimates from seven countries worldwide [33]. As previously mentioned projections for HIV/AIDS are debatable. Some have estimated that HIV/AIDS will be the leading worldwide cause of disease burden in 2030, as well as the leading cause among low and middle-income countries [31]. This is likely an overestimate, but experts agree that HIV/AIDS will remain a very serious global challenge [32]. This is particularly obvious when considering that, only 3 million people in LMI countries were receiving ART by December 2007 [34].
2) Preventable Behavioral Risk Factors
Ethnicity, obesity/diet/inactivity, insulin resistance, family history, and intrauterine environment are factors that contribute to the development of type 2 diabetes [7]. However, the leading risk factors for type 2 diabetes are diet and physical inactivity, which are behavioral in nature and largely preventable (although societal, cultural, political and psychological level factors should be considered). Overweight and obesity, along with physical inactivity have been shown to provide a “convincing increasing risk” for the development of type 2 diabetes [35]. The risk of developing the disease can be reduced and the effects of the disease can be mitigated through voluntary weight loss and regular physical activity.

In comparison, the leading risk factors for HIV/AIDS are sexual transmission (including unsafe heterosexual sex including commercial sex and men who have sex with men), injection drug use, and unsafe blood. UNAIDS has stated: “Unlike some infectious diseases, transmission of HIV is mediated directly by human behaviour, so changing behaviours that enable HIV transmission is the ultimate goal or outcome required for HIV prevention”[36]. Most of the HIV/AIDS infections prevalent in 2001 were acquired through heterosexual sex [28]. However, it should be noted that leading modes of transmission vary country by country and region by region. For example, heterosexual intercourse remains the driving force behind the epidemic in Sub-Saharan Africa, while HIV transmission in Latin America is largely attributable to men who have sex with men, sex workers, and injecting drug users [34]. For example, one recent study in Mexico found that 57% of the estimated 182,000 PLWHA are men who have sex with men [37].

3) Cost/Expenditures
Countries vary widely in the amount of resources they spend on diabetes and HIV/AIDS. However, the per capita expenditure on HIV/AIDS far exceeds that of diabetes. The annual global health expenditure for diabetes in 2007 was estimated to be between $232 and $421 billion, with the United States spending $119 billion, and only 20% (between $46.4 billion and $84.2 billion) being spent in low and middle-income countries [7]. This cost is expected to rise to between $302 billion and $558 billion in 2025, accounting for only changes in population size, age, sex, and degree of urbanization. The American Diabetes Association has estimated that two-thirds of the cost of diabetes is due to medical expenditures, and one third is due to reduced national productivity [38]. If obesity continues to increase globally, these cost predictions could be even higher. This “expenditure” reflects only resource availability, and not resource need, which is largely unmet, particularly in LMI countries. See Table 1.

UNAIDS estimates that spending on HIV/AIDS in LMI countries rose from US $292 million in 1996 to US $10 billion in 2007. However, UNAIDS notes: “Despite a global mobilization of resources that is unprecedented with respect to management of chronic illness in low- and middle-income countries – generating an estimated US $10 billion in financing in 2007 – it is apparent that significantly more funding will be needed to achieve universal access [to HIV prevention, treatment, care and support]” [39]. In fact, the 2007 UNAIDS financial analysis

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1 In 2001 at the Special Session on HIV/AIDS at the United Nations General Assembly (UNGASS), countries unanimously endorsed the “Declaration of Commitment on HIV/AIDS,” setting forth targets to strengthen the response to the epidemic. This move led to the 2006 High Level Meeting on HIV/AIDS at the United Nations General Assembly, which produced the “Political Declaration on HIV/AIDS.” This document committed all UN Member States to “pursuing all necessary efforts to scale-up nationally driven, sustainable and comprehensive responses to achieve broad multisectoral coverage for prevention, treatment, care and support with full and active
claims that to meet the goal of universal access by 2010, financial resources must increase to $42.2 billion annually and continue to rise to $54 billion by 2015. This is due to the cost of the new cases of HIV/AIDS that are added each year, in addition to the costs of keeping people alive.

The striking difference in the number of people living with each of these diseases should be noted: the number of people living with diabetes is nearly 7.5 fold that of HIV/AIDS. While both diseases clearly have devastating effects on individuals living with them, international assistance for HIV/AIDS has far outpaced support for other chronic diseases, including diabetes, as described previously. This may be due to strong political support for HIV/AIDS, which has received unprecedented attention in the global health arena [30, 41]. However, the cost of pharmaceuticals to treat HIV is extraordinarily high and contributes significantly to overall expenditures on the disease, although prices vary significantly by country. See Table 1.

Consequently, the financial burden of diabetes frequently falls on national governments alone, without external assistance that frequently accompanies their HIV/AIDS epidemic. There is a remarkable difference in the expenditure on the two diseases in low- and middle-income countries. Although overall expenditure is higher for diabetes than for HIV/AIDS across all income levels due to the sheer number of people living diabetes, more money is spent per capita on people with HIV/AIDS. Between seven and 14 times more money is spent on HIV/AIDS compared to diabetes in low and middle-income countries, and between five and eight times more money is spent on HIV/AIDS compared to diabetes in high-income countries. More important to note is that there is a 20 fold difference in per capita expenditure on diabetes in low and middle-income countries versus high income countries, while there is only a seven-fold

participation of people living with HIV, vulnerable groups, most affected communities, civil society and the private sector, towards achieving the goal of universal access to comprehensive prevention programs, treatment, care and support by 2010.”

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**Table 1: Comparison of Prevalence and Expenditure by Disease in 2007**

<table>
<thead>
<tr>
<th></th>
<th>Diabetes Mellitus</th>
<th>HIV/AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Percent prevalence</strong></td>
<td>6%</td>
<td>0.8%</td>
</tr>
<tr>
<td><strong>People living with disease</strong></td>
<td>246 million</td>
<td>33 million</td>
</tr>
<tr>
<td># in low and middle-income countries</td>
<td>196.8 million</td>
<td>31.4 million</td>
</tr>
<tr>
<td># people receiving ART in low and middle income countries</td>
<td>NA</td>
<td>3 million</td>
</tr>
<tr>
<td># in high income countries</td>
<td>49.2 million</td>
<td>1.6 million</td>
</tr>
<tr>
<td><strong>Total estimated global expenditure (2007)</strong></td>
<td>US $232 - $421 billion</td>
<td>US $10 billion*</td>
</tr>
<tr>
<td>Low and middle-income countries</td>
<td>US $46 – $84.2 billion</td>
<td>US $10 billion</td>
</tr>
<tr>
<td>High income countries</td>
<td>US $185 – $336 billion</td>
<td>Unavailable</td>
</tr>
<tr>
<td><strong>Average annual expenditure for care per person in low and middle income countries</strong></td>
<td>$233 - $429/person</td>
<td>US $3,333/person</td>
</tr>
<tr>
<td><strong>Average annual expenditure per person for care in high income countries</strong></td>
<td>$4735 - $6829/person</td>
<td>$24,000-$56,000†</td>
</tr>
</tbody>
</table>

* estimate only includes funds for low and middle-income countries
Sources: International Diabetes Federation 2006, UNAIDS 2008, †Estimate only for the United States as of 2005 [40]
difference in per capita expenditures on HIV/AIDS. This indicates that care for diabetes could be seriously underfunded in low and middle-income countries and too-expensive in high income countries. See Table 1. This difference may also speak to the marginalization of diabetes and other chronic conditions in low and middle-income countries, compared to high income countries.

4) Commonalities in management of disease
It is worth exploring the health system response to these diseases in tandem because their overall management is similar. These chronic diseases, punctuated by episodic acuity, require a comprehensive approach, including: diagnosis, patient self-monitoring, psycho-social support, and on-going medical monitoring and treatment that will accrue significant expenditures for the rest of the life of the patient. Chronic diseases and their care follow a continuum, such as that presented by Nolte, based on Peterson and Kane’s 1997 work [19, 42]. I have adapted this continuum below in Figure 1. First, both diseases require testing/diagnosis. In the case of diabetes, although no definitive studies have shown that early detection and treatment reduce long-term complications [43], detection and prompt treatment may reduce the burden of diabetes and its complications [44]. Early detection for HIV/AIDS is critical to preventing the spread of further disease as well as slowing the virus and maintaining one’s immune system. Early treatment has also been proven to reduce mortality by 70% among people with HIV [45]. This requires a system to be in place to screen populations most at risk for developing these diseases.

**Figure 1: Health and health system management continuum**

Source: Adapted from Nolte and McKee 2008 and Peterson and Kane 1997.

Once diagnosed, the patient moves into the disease management phase\(^2\). A critical piece of this is patient education about the disease and how to manage it; this is critical to achieving a certain level of self-monitoring and care [19]. For a person with diabetes, this means regularly monitoring his/her glucose levels, counting carbohydrate intake and healthy eating, routinely examining their feet, and regularly taking any pharmaceutical products, such as oral agents or insulin, as directed by his/her physician. For a person living with HIV/AIDS, this entails healthy eating, regularly taking his/her antiretroviral medications, and avoiding behaviors that may spread the disease to others.

Self-care is complemented by professional health care, and includes routine examinations, laboratory exams, and adjustments to medications. For example, persons with diabetes need

\(^2\) This does not refer to specific disease management programs, but rather to overall management or care for the person living with the disease
regular monitoring by trained health care providers to check their HbA1C, cholesterol, and triglyceride levels; to check for signs of retinopathy; to check for kidney problems; to ensure their feet are healthy; and to adjust medications [46]. Persons living with HIV/AIDS require routine medical examinations, viral load testing or CD4 counts, and adjustments to medications. Routine examinations are important, as both diseases frequently are accompanied by comorbidities that can pose a significant threat to the health of the person.

These comorbidities or their complications frequently are the causes of periodic acute care. In the case of diabetes, comorbidities could include stroke, heart disease, or hypertension. In the case of HIV/AIDS, common comorbidities include tuberculosis, pneumonia, or other opportunistic infections. These comorbidities raise the level of complexity of care the patient must receive, and consequently frequently raise the cost of the care [19]. The nature of both diseases requires that the patient receive regular medical care, including pharmaceuticals, for the rest of his/her life. This comes with a hefty price tag, as described above, particularly as the disease progresses with time or age, as well as with periodic episodes of acute illness or complications. Furthermore, a person living with either disease may require significant psychosocial support as he/she adjusts to his/her disease status and learns to manage it.

Addressing these diseases means directly or indirectly addressing the health systems in which they are prevented, diagnosed, and treated. Given the vast amount of resources being utilized to address these diseases, a close examination of the impact on health systems is warranted. Are the diseases approached in a silo-ed manner? Are they approached in an integrated way? What are the outcomes for the system (i.e. Do expenditures rise or fall? Are the systems operating more efficiently?)? What are the outcomes for the patient (i.e. do they remain healthy longer, with shorter, less frequent periods of acute illness?)?

Why examine Mexico and Brazil?
Mexico and Brazil are two middle-income, Latin American countries that have many similarities, but also have some differences in their national health systems that are interesting to examine. The countries have the largest populations in Latin America, including having similar age structures, birth and death rates, fertility rates, and life expectancies (See Table 2). Brazil is more ethnically diverse than Mexico, but both have significant Amerindian populations, large rural populations in contrast with massive urban centers, fairly high literacy rates, and similar educational achievement levels.

A country’s ability to respond to disease through its health system is often driven by socioeconomic factors. Low-income countries are frequently dependent on external sources of aid to build or reform their health care systems³. High-income countries often invest their own significant resources in their health care systems. Middle-income countries are somewhere in between, frequently with some level of external financial support but largely dependent on their own developing economies to sustain their health systems. These countries are often strained by huge socioeconomic and health disparities within their borders. Nonetheless, the experiences of

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³ Low, middle and high-income countries are defined using criteria developed by the World Bank based on a number of standard indicators, including national income per capita. This terminology was selected over “developed and developing countries.” because it offers a more precise distinction among countries.
middle-income countries in health sector reform can be used to inform policy-makers in countries of all income levels.

Table 2: Basic demographic information for Mexico and Brazil

<table>
<thead>
<tr>
<th></th>
<th>Mexico</th>
<th>Brazil</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population (July 2008 est.)</td>
<td>109,955,400</td>
<td>196,342,592</td>
</tr>
<tr>
<td>Age Structure</td>
<td>0-14 years: 29.6%</td>
<td>0-14 years: 27%</td>
</tr>
<tr>
<td></td>
<td>15-56 years: 64.3%</td>
<td>15-64 years: 66.8%</td>
</tr>
<tr>
<td></td>
<td>65+ years: 6.1%</td>
<td>65+ years: 6.3%</td>
</tr>
<tr>
<td>Birth rate</td>
<td>20.4 births/1000 population</td>
<td>18.74 births/1000 population</td>
</tr>
<tr>
<td>Death rate</td>
<td>4.78 deaths/1000 population</td>
<td>6.35 deaths/1000 population</td>
</tr>
<tr>
<td>Fertility rate</td>
<td>2.3 children/woman</td>
<td>2.3 children/woman</td>
</tr>
<tr>
<td>Life expectancy at birth</td>
<td>75.84 years</td>
<td>71.71 years</td>
</tr>
<tr>
<td>Ethnic groups</td>
<td>Mestizo(Amerindian-Spanish): 60%</td>
<td>White: 53.7%</td>
</tr>
<tr>
<td></td>
<td>Amerindian: 30%</td>
<td>Mulatto (Mixed white &amp; black): 38.5%</td>
</tr>
<tr>
<td></td>
<td>White: 9%</td>
<td>Black: 6.2%</td>
</tr>
<tr>
<td></td>
<td>Other: 1%</td>
<td>Other, incl Amerindian: 0.9%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unspecified: 0.7%</td>
</tr>
<tr>
<td>Urban population (%)</td>
<td>76%; Mexico City est. population: 19 Million</td>
<td>81%; Sao Paolo est. population: 18.8 million</td>
</tr>
<tr>
<td>Literacy rate: Average years of school attendance:</td>
<td>91% 8 years (2005 est.)</td>
<td>88.6% 6.2 years (2002 est.)</td>
</tr>
</tbody>
</table>

Sources: [47-50]

As middle-income countries, Mexico and Brazil are strong economic forces within Latin America, with strong agricultural, manufacturing, and service sectors. Mexico was estimated to have a Gross Domestic Product (GDP) of $893.36 billion in 2007, and Brazil was estimated to have a GDP of $1,314.17 billion; Mexico’s GDP per capita was higher than that of Brazil, $12,400 compared to $9,500 respectively [47]. Despite strong economic growth and development over the past few decades, both countries are marked by significant income inequalities between the richest and poorest segments of the population, strongly correlated to the countries’ various regions and ethnic groups [51].

Both countries have recently undergone significant reform to their public health systems. The 1980s marked a series of significant reform for both countries, although prior reforms date back to the 1930s in the case of Mexico. In 1988, with the adoption of the new Federal Constitution, Brazil created the Unified Health System (SUS), which was guided by the principles of “universal and equitable access to services for the promotion, protection and recovery of health, integrated in regionalized, multilevel network under the responsibility of the three levels of government (federal state, and municipal)” [51, 52]. Similarly, Mexico passed a constitutional amendment in 1983, which established the right of every person to the protection of his/her health [53, 54]. Additional significant reforms continued in Mexico throughout the 1990s and into the current decade (such as the creation of a new public insurance scheme) while Brazil has not undertaken further significant reforms (of the same magnitude).
Both countries spend relatively small proportions of their GDP on health, compared to high income countries. As of 2005, Mexico spent 6.4% of its GDP on health (approximately $49.13 billion), an increase over its 2000 spending of 5.6%, while Brazil spent 7.9% of its GDP in 2005 (approximately $69.72 billion), compared to 7.2% in 2000 [55]. Per capita total expenditure on health in Mexico rose from $327 to $424 between 2000 and 2005, and per capita total expenditure on health in Brazil rose from $267 to $371 over the same period (Ibid).

The reforms to both national health systems, their roots, and their impact have been well-documented. The reforms in Mexico and Brazil during the 1980s had roots in the concept of “solidarity” and built upon the primary health care movement springing from World Health Organization’s Declaration of Alma Ata in 1978. However, Brazil was also undergoing a massive transformation from a government dictatorship to democracy, and the concepts of citizenship and respect for human rights also contributed to establishing access to health care as a constitutional right [56]. The most recent reforms in Mexico have been attributed to the pressures on the health system due to the double burden of disease [54, 57]. Meanwhile, Brazil seems to have taken a more incremental approach in furthering reforms, particularly as related to its disease burden. Its last major social reforms were oriented towards the eradication of extreme poverty and hunger, but not specific health issues [51].

Table 3: Comparison of Prevalence & Expenditure by Disease in Brazil and Mexico, 2007

<table>
<thead>
<tr>
<th>MEXICO</th>
<th>Diabetes Mellitus</th>
<th>HIV/AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Percent prevalence</strong></td>
<td>10.6</td>
<td>0.3</td>
</tr>
<tr>
<td><strong>People living with disease</strong></td>
<td>6,115,700</td>
<td>200,000</td>
</tr>
<tr>
<td><strong>People receiving ART</strong></td>
<td>NA</td>
<td>44,016</td>
</tr>
<tr>
<td><strong>Total estimated expenditure</strong></td>
<td>US $3,461,699,000</td>
<td>US $339,791,000†</td>
</tr>
<tr>
<td><strong>Expenditure for care and treatment</strong></td>
<td>US $3,461,699,000</td>
<td>US $259,783,000†</td>
</tr>
<tr>
<td><strong>Average expenditure per person for Care (expenditure for care &amp; treatment/# people on treatment)</strong></td>
<td>US $566</td>
<td>$5823</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>BRAZIL</th>
<th>Diabetes Mellitus</th>
<th>HIV/AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Percent prevalence</strong></td>
<td>6.2</td>
<td>0.6</td>
</tr>
<tr>
<td><strong>People living with disease</strong></td>
<td>6,913,000</td>
<td>730,000</td>
</tr>
<tr>
<td><strong>People receiving ART</strong></td>
<td>NA</td>
<td>181,000</td>
</tr>
<tr>
<td><strong>Total estimated expenditure</strong></td>
<td>US $2,158,335,000</td>
<td>US $534,962,000</td>
</tr>
<tr>
<td><strong>Expenditure for care and treatment</strong></td>
<td>US $2,158,335,000</td>
<td>US $438,852,000</td>
</tr>
<tr>
<td><strong>Average expenditure per person for Care (expenditure for care &amp; treatment/# of people on treatment)</strong></td>
<td>US $312</td>
<td>$2,424</td>
</tr>
</tbody>
</table>


Mexico and Brazil have similar epidemiological profiles, including a high burden of chronic disease. Specifically, these countries have the greatest number of people living with HIV and type 2 diabetes mellitus in Latin America. See Table 3. Both have guaranteed universal access to anti-retroviral therapy (ART) for PLWHA, but Brazil has come closer to achieving this goal.
As of 2006, it was estimated that 76% of people needing ART in Mexico were receiving it, compared to 85% in Brazil [58]. In comparison, Mexico has made substantial efforts to focus on its very heavy burden of diabetes, while Brazil has seemingly lagged behind. For example, two of the major public health entities in Mexico have begun programs to address diabetes prevention and care, while the Brazilian Ministry of Health appears to have few major activities specific to diabetes prevention or care currently underway. The commitment to universal access for ART, as well as the care for people with diabetes, carry significant economic implications for both countries (See Table 3). Questions have been raised in both countries regarding the sustainability of this expense for the national governments.

The Problem

There is little discussion in the public health literature regarding how middle-income countries are reforming their health systems to address their burgeoning chronic disease burden. There is a plethora of available material about how to manage chronic diseases, particularly in high-income countries. There is also significant literature chronicling health sector reform efforts in countries of all income levels. However, few materials seem to specifically address how health sector reform efforts intersect with scientific evidence about chronic disease and its management. Furthermore, there is a gap in the literature about how the plethora of chronic disease management models inform overall national health system organization. Many scientists are now examining the role that global efforts around HIV/AIDS have had on health system development or reform, particularly in low-income countries. However, none seem to be examining the specific impact of other chronic diseases, such as diabetes, in middle-income countries where the disease burden exceeds that of HIV/AIDS. The current work aims to address this specific gap by examining the public health system responses to both diabetes and HIV/AIDS in the middle income countries of Mexico and Brazil.

Research Questions/Specific Aims

The goal of the current study is to answer a series of questions through development of a conceptual framework to evaluate public health system responses to chronic diseases and case studies examining the public health system responses in Mexico and Brazil.

**General:** How can middle-income countries structure their public health systems to most address their burgeoning chronic disease burden effectively?

**Specific:** How have Mexico and Brazil structured their public health systems to respond to HIV/AIDS and to diabetes?

**Secondary:** 1) What models can be used to evaluate a health system’s response to chronic disease?
   1. What does the burden of HIV/AIDS and diabetes look like in Mexico and Brazil?
   2. How have recent public health system reforms responded to HIV/AIDS and to diabetes in Mexico and Brazil?
   3. What lessons and policy recommendations can be drawn from the experiences in these two countries that will be of use to other countries, specifically low and middle-income countries?
References


Introduction to National Health Systems for Chronic Care

Health systems around the world have historically been oriented toward acute care, largely responding to an infectious disease burden, particularly in low and middle-income (LMI) countries [1-4]. However, over the past century, mortality attributable to infectious disease has declined significantly, and chronic diseases have become the leading cause of death globally [5, 6]. For the purposes of the current study, chronic disease is characterized by a long duration, slow progression, and unlikelihood of a cure [7-10]. This characterization includes persistent communicable diseases, such as HIV/AIDS, as well as non-communicable diseases (diabetes). Chronic diseases cannot be successfully managed through a conventional acute care approach, but rather require a more integrated, complex and sustained response from the health system [11-14]. Models to provide care for patients with complex or chronic conditions began to emerge in the late 1980s and are rooted in the concept of integration [14]. Around the same time, interest in examining and reforming health systems became popular, and models and frameworks for how health systems operate began to emerge [15].

The growth in chronic diseases is implicitly linked to the challenges faced by many health systems: rising health care costs, meeting the expectations of the population to improve health, and limits on capacity to pay. Still, little can be found in the literature that clearly connects chronic disease care to overarching national health system design and reform. The purpose of the current paper is to examine models for health systems and chronic disease care and develop a new model that can be utilized to examine how health systems respond to chronic disease.

Living with Chronic Disease

Living with a chronic disease is different from experiencing an acute disease or illness. In the case of an acute illness, a person may become ill, seek medical attention, receive a diagnosis, and receive one-time outpatient or inpatient care until cured and returned to a completely healthy state. A person with a chronic disease experiences a different pattern. Chronic diseases, punctuated by episodic acuity, require a comprehensive approach, including: diagnosis, patient self-monitoring, psycho-social support, and on-going medical monitoring and treatment that will accrue significant expenditures for the rest of the life of the patient. Chronic diseases and their care follow a continuum, such as that presented by Nolte, based on Peterson and Kane’s 1997 work [14, 16]. This continuum is adapted below in Figure 1. Moving from left to right along the spectrum, an individual moves from a healthy state to an unhealthy state, requiring diagnosis.

Once diagnosed, the patient moves into the disease management phase (Note: this does not refer to specific disease management programs, but rather to overall care). Effective patient education about the disease and how to maintain appropriate self-monitoring and care are central elements of successful disease management program [14]. Even with successful self-management, however, most patients will likely experience periodic complications requiring acute care. Consequently, a typical patient will move back and forth between disease management and acute care multiple times over the course of their disease.
Figure 1: Health and health system management continuum

Source: Adapted from Nolte and McKee 2008 and Peterson and Kane 1997.

Integration and Care for Chronic Disease

A number of approaches to chronic disease care have been developed over the past two decades. The foundation of many of these approaches is the concept of “integration” [17]. Many other terms with similar meanings have also been employed to describe this concept broadly or aspects of it, such as “coordination” and “continuity.” These models recognize the complexity of care that is involved in treating a person with a chronic disease, and that the care response is often multifaceted [13]. The complexity requires different pieces of a health care system to work together toward the ultimate goal of achieving cost-effective quality care for persons with chronic diseases [17]. This approach keeps with a central tenant of organizational theory, “the greater the differentiation, the greater the need for integration” [18].

Axelsson and Axelsson propose that the concept of integration has its roots in organizational theory, namely contingency theory, as developed by Lawrence and Lorsch [19]. Contingency theory posits that organizational design depends on or is “contingent” upon environmental conditions [20]. Scott and Davis summarize Lawrence and Lorsch’s theory saying:

“…the match or co-alignment of an organization with its environment occurs on at least two levels: (1) the structural features of each organizational subunit should be suited to the specific environment to which it relates; and (2) the differentiation and mode of integration characterizing the larger organization should be suited to the overall complexity in the environment in which the organization must operate.”

Integration was first contemplated by the health care sector in the 1970s and 1980s when physicians became interested in applying systems theory and organizational design to the healthcare field [21]. As quoted in Axelsson and Axelsson, integration is defined as “the quality of the state of collaboration that exists among departments that are required to achieve unity of effort by the demands of the environment” [19]. Integration, in a health care context, was defined by Leutz as “the search to connect the healthcare system (acute, primary medical, and skilled) with other human service systems (e.g. long term care, education, and vocational and housing services) in order to improve outcomes (clinical, satisfaction, and efficiency)” [22]. Kodner and Spreeuwenberg defined it as “a coherent set of methods and models on the funding, administrative, organizational, service delivery and clinical levels designed to create
connectivity, alignment and collaboration within and between the cure and care sectors” [21]. Others such as Hardy et al have developed similar definitions that link health and social services [17].

These authors have also described a goal of integration as benefiting those with chronic diseases or conditions. For example, Kodner and Spreeuwemberg define the goal of integrated models and methods as “enhancing quality of care and quality of life, consumer satisfaction and system efficiency for patients with complex, long term problems, cutting across multiple services, providers and settings” Leutz also places the goal around those with “physical, developmental, or cognitive disabilities – often with related chronic illnesses or conditions” [22]. Addressing the needs of those living with chronic conditions may not have been the initial goal of those individuals and organizations implementing integrated models, but in many cases now doing so is at the core of their operations.

Integration that blends cure and care sectors is frequently described as “horizontal,” while “vertical integration” can imply integration between levels of care (primary, secondary, and tertiary). Vertical integration is also sometimes used to mean that payers and providers are part of a single organization [23, 24]. However, the dichotomy between vertical and horizontal is overly simplistic. Kodner and Spreeuwemberg as well as others describe the types of integration in more complex terms, such as funding, administrative, organizational, service delivery, and clinical. The overarching message from both Leutz and Kodner and Spreeuwemberg is that there are many variations of integrated care, and patients with particularly complex conditions, such as those with chronic diseases, “demand a complex solution, necessitating more, and more structured forms of integration from several of the operational domains described above” [21]. Integration has other dimensions, described by Nolte and McKee as breadth, degree, and process, which result in much variation across health care systems. These dimensions will not be explored here, but should be kept in mind as factors that contribute to an overall systemic approach to addressing chronic disease.

In effect, contingency theory and integration are at the root of this work. These theories draw our attention to how a health system is located within and is responsive to the larger environment, including rapidly growing chronic disease burdens that are complex and require both ongoing and sometimes acute care, provided by highly skilled specialists. These chronic care burdens necessitate an integrated approach by the health system. While the notion of integration is quite logical, Nolte and McKee point out that there is a paucity of empirical evidence on the consequences of the different forms of integration, coordination and chronic care models [17].

**Models of Care for Chronic Disease**

The precursor to perhaps the most well-known model for addressing chronic care, the “Chronic Care Model” (CCM), was developed in 1998 by Edward Wagner after a review of the effectiveness of 72 chronic disease management programs [25]. He finalized the model in 2001, which is “designed to help practices improve patient health outcomes by changing the routine delivery of ambulatory care through six interrelated system changes meant to make patient-centered, evidence-based care easier to accomplish” [26]. The six CCM elements include:
health system organization, community resources, self-management support, delivery system design, decision support, and clinical information systems. See Figure 1a and 1b.

Figure 1a: The CCM

<table>
<thead>
<tr>
<th>Element</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Resources &amp; Policies</td>
<td>Supportive or educational resources otherwise unavailable in health care system</td>
</tr>
<tr>
<td>Health care organization</td>
<td>Larger provider organizational level;</td>
</tr>
<tr>
<td>Self-management support</td>
<td>Collaboratively helping patients &amp; families acquire skills &amp; confidence to manage illness</td>
</tr>
<tr>
<td>Delivery system design</td>
<td>Medical practice structure separating acute care from planned management of chronic cases</td>
</tr>
<tr>
<td>Decision Support</td>
<td>Interventions directed at improving the knowledge and skills of providers</td>
</tr>
<tr>
<td>Clinical information systems</td>
<td>Information technology to provide data on patients and populations</td>
</tr>
</tbody>
</table>


In this model, the term “health system organization” refers to organization at the practice level, specifically the provider organization, and not a broader concept of the entire set of organizations that are focused on producing health (which is a definition of health systems that will be discussed in the next section) [27]. Four components reside in the realm of “health system organization;” the definitions of each, as well as of “Community Resources & Policies” are described in Figure 1b.

The CCM has been implemented extensively in a number of contexts and evaluated by numerous groups for impact on quality of care, clinical outcomes, and resource use. Each of the six elements has been subdivided into various components for the measurement of quality improvement by various authors [28]. One common set of components is found in Table 1.

The evidence surrounding the effectiveness of the CCM has been mixed. One meta-analysis determined that most of the evidence pertains to patient self-management support, delivery system design, decision support, and clinical information systems (particularly patient outcome measures were self-management support and delivery system design), but does not fully address the organization of health care providers nor the role of resources and policies in the community [29]. However other reviews have found that different pieces or combinations were more critical [26]. Nolte and McKee summarized the multiple single and meta reviews of the CCM, noting, “while there is now ample evidence that single or multiple components of the CCM improve selected processes and outcomes of care, it is less clear whether the model as a whole is essential to achieve the same benefits” [17].
In addition lacking clarity about which elements or combination of elements are essential to improved health outcomes, the CCM has been critiqued on multiple other fronts since its inception. The model has been most frequently been reviewed in the context of specific diseases such as diabetes, hypertension, asthma, and heart disease [17, 29]. However, as discussed previously, many individuals live with more than one chronic disease, and the model has not been evaluated as thoroughly among persons with multiple chronic conditions [17]. Furthermore, concerns over the sustainability of outcomes related to implementing the CCM have been raised, and little research has been focused on this issue [30].

Another important aspect is the cost and cost-effectiveness of implementing the CCM. It has been widely noted that health care practices and organizations must spend a significant amount of time and resources to fully implement the CCM [26]. Costs can include extensive training, hiring of new staff, purchasing of new technology, as well as lost revenue due to reduced patient load to accommodate trainings, meetings, installations, etc. Many of these costs are one-time and front-end, with the expectation that improvements will help recapture some of the revenues. However, the evidence on this remains somewhat shaky. One study reviewed 27 articles that studied interventions related to the CCM and their impact on health care use or cost for patients with congestive heart failure, asthma, and diabetes [27]. Of these, 18 demonstrated reduced health care costs or lower use of health care services. Since many of the recommendations and changes suggested by the CCM may not be reimbursable by payers in fee-for-service models, some costs may never be recuperated, unless performance incentives are offered. The CCM model may be more easily implemented, from a cost-perspective, in closed or capitated systems. As Bodenheimer et al point out, to create a favorable business case for implementing the CCM, the savings or revenues must accrue to the organization paying for the improvements.

Lastly, some have critiqued the model as being too prescriptive in that patients must “fit within a clinical pathway or map” instead of taking a more open or specific model based on the needs of the individual [31]. This critique raises the valid concern that the patient/individual does not appear at the center of the model, common in other health models, such as the socio-ecological model. Rather, the CCM places the individual as a sidelined recipient of care that is part of a larger, ongoing system, as opposed to an active player in the processes going on around him/her.

---

**Table 1: Frequently measured aspects of the six critical components of the CCM**

<table>
<thead>
<tr>
<th>Community Linkages</th>
<th>Self Management Support</th>
<th>Delivery System Design</th>
</tr>
</thead>
<tbody>
<tr>
<td>For patients</td>
<td>Patient education</td>
<td>Care management roles</td>
</tr>
<tr>
<td>For community</td>
<td>Patient activation/psychosocial support</td>
<td>Team practice</td>
</tr>
<tr>
<td></td>
<td>Self-management assessment</td>
<td>Care delivery/coordination</td>
</tr>
<tr>
<td></td>
<td>Collaborative decision making with patients</td>
<td>Proactive follow-up</td>
</tr>
<tr>
<td></td>
<td>Guidelines available to patients</td>
<td>Planned visit</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Visit system change</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Health Care Organization</th>
<th>Decision Support</th>
<th>Clinical Information Systems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leadership support</td>
<td>Institutionalization of guidelines/prompts</td>
<td>Patient registry system</td>
</tr>
<tr>
<td>Provider participation</td>
<td>Provider education</td>
<td>Use of information for care</td>
</tr>
<tr>
<td>Coherent system improvement and spread</td>
<td>Expert consultation support</td>
<td>Management</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Feedback of performance data</td>
</tr>
</tbody>
</table>

Some might recognize commonalities between the CCM and a frequently-employed public health model referred to as the “socio-ecological model” [32]. This model dates back to 1988 and basically posits that the individual’s health is affected by any number of influences around him clustered by level of proximity, and consequently health interventions could be directed at any one of the levels: individual, interpersonal, organizational, community and public policy.

In response to these critiques, and to make the model more translatable to a primary health care environment, common in low and middle-income countries, the WHO, in collaboration with Wagner, adapted the CCM in 2002. The “Innovative Care for Chronic Conditions Framework” (ICCCF) places the relationship between community partners, the health care team, and patients and families at the center of the model (termed “micro-level”), surrounded by the broader community and health care organization (“meso-level”), and positive policy environment (macro-level). This model is complemented by their identification of eight essential elements for taking action to successfully manage chronic diseases. See Figure 2 and Table 2.

This model lends itself much better to a broader, national health system context, than its forerunner, which is largely oriented to provider practices. Integration of action at multiple levels is at the core of this model. In this sense, it mimics the core concept of the socio-ecological model, which nests the individual at the center of expanding concentric environmental circles of the interpersonal, organizational, community, and public policy environments [32]. It takes into account the broader socio-political environment by including emphasis on intersectoral policies, legislative frameworks, and advocacy.

**Figure 2: ICCCF Model**

![Innovative Care for Chronic Conditions Framework](source: WHO 2002)
Table 2: 8 Essential Elements

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Support a paradigm shift from acute episodic care to one more suitable for those living with chronic conditions</td>
</tr>
<tr>
<td>2</td>
<td>Manage the political environment to ensure commitment</td>
</tr>
<tr>
<td>3</td>
<td>Build integrated health care to insure share information across settings and providers, including financing, prevention and community resources</td>
</tr>
<tr>
<td>4</td>
<td>Align sectoral policies for health, including labor, agriculture, education</td>
</tr>
<tr>
<td>5</td>
<td>Use health care personnel more effectively</td>
</tr>
<tr>
<td>6</td>
<td>Center care on patient and family</td>
</tr>
<tr>
<td>7</td>
<td>Support patients in their communities</td>
</tr>
<tr>
<td>8</td>
<td>Emphasize prevention</td>
</tr>
</tbody>
</table>

Source: WHO 2002

This model also speaks to the need for “consistent and sustainable financing” for chronic care given that people with chronic diseases will likely use services on a regular basis. The WHO further notes that some chronic care patients without insurance may face catastrophic health expenditures and significant loss of quality of life if their conditions go untreated [4]. The original CCM does not directly address this, although subsequent critiques discussed above point to the problems of implementing the model due to health care financing structures in the United States, in particular. This model also emphasizes the role of the community in a bigger way than the original CCM to not only provide support to the patient, but also as a potential source of financing in poor countries where additional resources may be needed. However, this does not imply developing additional disease-specific funding and programming. In fact, an “integrated” approach, in this context, would imply an emphasis on primary care that would not only enable the treatment of complex comorbidities, but would also require a breakdown of tradition “vertical” disease funds, such as those for HIV/AIDS and diabetes, something the WHO proposes [4].

The WHO provides some case study evidence to support the utility of the ICCCF. However, unlike the CCM, no review or study demonstrating its impact on quality, clinical outcomes, or resource use could be identified. Multiple other variations of the CCM have also been developed around the world [33]. For example, the Expanded Chronic Care Model was developed in 2003 by a group in Canada (See Figure 3) [34]. Similar to the ICCCF, it expands the role of the community as well as the policy environment. It is beyond the scope of this paper to explore and critique each variation of the CCM here. However, it is worth noting that many build enhanced elements of prevention, community and policy intervention.

Other models have been developed that share common elements of the CCM models. Kaiser Permanente, a “fully integrated system,” was an early implementer of internal disease management programs that demonstrated significant improvements in care processes and health outcomes [35]. Their approach has frequently been illustrated with what has become known as the Kaiser Permanente Triangle [17, 36]. See Figure 4.
None of the variations of the CCM directly address the issue of episodic acute care that individuals will occasionally experience, either related to their chronic disease or something else (e.g., the flu). It seems that these models assume a degree of integration into a larger health system scenario where the appropriate linkages to acute care can be made. This is more evident in the Kaiser model, as a fully integrated system, although the triangle does not visually display this element.

This approach to chronic care is population-oriented, dividing individuals into groups based on their level of need. Supported self-care, disease management, and case management correspond to the increasing level of user need, as well as to the level of integration[17]. However, the organization recognized the need to move away from a condition-centric approach to a broader-based, comprehensive approach that incorporates prevention and accounts for patients with multiple chronic comorbidities. Consequently, it has applied the CCM across the organization, and some have credited physician leadership and involvement with its successful implementation at Kaiser Permanente [35]. The two models are not necessarily in conflict with each other, but rather the CCM enhances and broadens the overall approach.

Examining the components of care for chronic disease is the first step in the more complex process of preparing national health systems to deal with their growing chronic disease burden. The key components identified in the aforementioned models include: public policy, financing (including appropriate incentives), information systems, self-management, well-organized health teams (delivery system design), well-equipped health teams (provider preparedness), supportive and active community, and an emphasis on prevention. However national health systems are not necessarily examined using the same rubric. The next section will discuss health system frameworks.
Models for National Public Health Systems and Health System Reform

Health Systems
Health systems have been defined a number of ways over the past three decades. The current study will utilize the WHO’s definition of health systems. The landmark 2000 World Health Report defined health systems as “comprising all the organizations, institutions, and resources that are devoted to producing health actions” [3]. It clarifies health actions as “any effort whether in personal health care, public health services, or through intersectoral initiatives, whose purpose is to improve health (Ibid). This definition allows for analysis of both public and private pieces of any health system within a country. The current study, however, will focus exclusively on the public health system response. This is defined as any publicly financed governmental health action at the federal, state, or other subnational level. The focus will be on national level actions and their impact on subordinate levels and will not explore individual subnational actions not mandated by the federal level.

In 1991, the seminal work, “National Health Systems of the World,” defined five categories of health system functioning [37]. These include:

- Production of resources (trained staff, commodities including drugs, facilities, and knowledge)
- Organization of programs (by government ministries, private providers, voluntary agencies)
- Economic support mechanisms (funding sources, such as tax, insurance, user contributions)
- Management methods (planning, administration, regulation, and legislation)
- Delivery of services (preventive and curative personal health services; primary, secondary, and tertiary services; public health services; services for specific populations, such as children, or for specific conditions, such as mental illness).

The 2000 World Health Report built upon this work and also defined the goals and functions of health systems. The three fundamental goals outlined in the report are: 1) improve the health of the population they serve; 2) responding to people’s expectations; and 3) providing financial protection against the costs of ill health (also described as fairness in financial contribution). It operationalizes the goals through four “vital functions”: 1) service provision; 2) resource generation; 3) financing; and 4) stewardship. The indicators used to describe achievement of these goals are found in Table 3. It is important to note that responsiveness, one of the indicators, is not a measure of how the system responds to health needs, which WHO points out would be measured by health outcomes. Rather, responsiveness speaks to how a system performs relative to non-health aspects, meeting or not meeting a population’s expectations of how it should be treated by providers[3]. Measuring the attainment of these goals was the objective of the 2000 World Health Report and remains an ongoing challenge to health systems experts globally.
Table 3: WHO Indicators of Attainment of Health System Goals

<table>
<thead>
<tr>
<th>Goal</th>
<th>Indicator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improving the health of the population</td>
<td>Disability Adjusted Life Expectancy (DALE)</td>
</tr>
<tr>
<td>Responsiveness to people’s expectations</td>
<td>Composite score from a key-informant survey that examined 3 dimensions of respect for persons and 4 dimensions of client orientation</td>
</tr>
<tr>
<td>Financial protection against health risk/ Fairness in financial contribution</td>
<td>Ratio of total health contribution to total non-food spending</td>
</tr>
</tbody>
</table>

Source: 2000 World Health Report

In 2007, WHO again furthered their work in health systems through their report “Everybody’s Business: Strengthening Health Systems to Improve Health Outcomes” [38]. This document outlines the “building blocks” of health systems, *vis a vis* the aforementioned goals. However, they added the additional goal of improved efficiency to the original three, which had been implicit in the model but described as performance. The measurement for efficiency or performance is achievement relative to resources, where achievement is comprised of health (weighted 50%), responsiveness (25%), and fair financial contribution (25%), taking distribution or equality into account. Figure 5 displays how these fit together. These complicated calculations have not been repeated on a global level since the 2000 World Health Report, although some individual countries have done further analysis.

The 2007 report also defined system building blocks as shown in Table 4 [38]. However, it did not develop specific process indicators for the building blocks. The report defined some key areas for which indicators could be developed, although they described the central elements (goals) for each building block, as well as priorities for the organization related to helping countries establish or achieve these.

Figure 5:

THE WHO HEALTH SYSTEM FRAMEWORK

Source: WHO 2007
Table 4: Definition of WHO Health System Building Blocks

| Service Delivery | Delivery of effective, safe, quality personal and non-personal health interventions to those who need them, when and where needed, with minimum waste of resources. |
| Health Workforce | Working in a responsive, fair, and efficient way to achieve the best health outcomes possible, given available resources and circumstances; i.e. there are sufficient numbers and mix of staff, fairly distributed, and they are competent, responsive and productive. |
| Information System | Ensuring that ensure the production, analysis, dissemination and use of reliable and timely information on health determinants, health systems performance, and health status. |
| Medical Products, vaccines, and technologies | Ensuring equitable access to essential medical products, vaccines and technologies of assured quality, safety, efficacy, and cost effectiveness, and their scientifically sound and cost-effective use. |
| Health Financing | Raising adequate funds for health in ways that ensure people can use needed services and are protected from financial catastrophe or impoverishment associated with having to pay for them. |
| Leadership/governance | Ensuring that strategic policy frameworks exist and are combined with effective oversight, coalition-building, the provision of appropriate regulations and incentives, attention to system-design, and accountability. |

Source: WHO 2007

Health System Reform

If health systems respond to disease, then what drives reform? Simply stated, it is the human and economic implications of the disease burden. Academics have presented numerous frameworks to describe the reasons for health sector reform. In 2000, the WHO described that the health system reforms during the course of the 20th century have been “prompted not only by perceived failures in health but also by a quest for greater efficiency, fairness and responsiveness to the expectations of the people that systems serve” [3].

These factors are similar to those proposed by Roberts et al. They defined “health sector reform drivers” as:

1) Rising costs: due to aging, increase in chronic disease burden, other epidemiological developments, new pharmaceuticals and new technologies
2) Rising expectations: derived from economic, social and political sources
3) Limited capacity to pay: restraints on fiscal capacities due to demand/cost outpacing economic growth or competing demands
4) Skepticism of conventional ideas: old models have been discredited, coupled with bad governance and poor policies, resulting in badly run public health systems and poor health services. [39]

There is significant overlap in these frameworks. Thus, for the purposes of this work, I posit that the implications of disease, 1) including rising costs of care and the government’s ability to pay for them, coupled with the 2) population’s expectations for fairness and responsiveness from the health system, and 3) past failed efforts in the health sector, may shape health sector reform.
Framework for evaluating how health systems have responded to chronic disease

Frameworks are useful tools to examine and evaluate how things are working. They can highlight desirable or critical attributes, as well as describe priority areas. As a result, they can help identify systemic weaknesses and gaps. However, no singular model has been developed to date that examines what national health system elements are critical for addressing chronic disease.

Comparing the model components with common terminology based on their definitions in a simple table (See Table 5) allows us to clearly identify commonalities among the models. Three elements emerge as common among all models: 1) financing, 2) policy, and 3) service delivery (interaction at the patient level). Working definitions will be presented later for each of these elements.

Table 5: Comparing components of chronic care and health system frameworks

<table>
<thead>
<tr>
<th></th>
<th>Chronic Care Models</th>
<th>Health System Models</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CCM</td>
<td>ICCC</td>
</tr>
<tr>
<td>1. Financing</td>
<td>✅</td>
<td>✅</td>
</tr>
<tr>
<td>2. Medical Products</td>
<td>✅</td>
<td>✅</td>
</tr>
<tr>
<td>3. Policy</td>
<td>✅</td>
<td>✅</td>
</tr>
<tr>
<td>4. Self-management support: Health literacy/education, psychosocial support</td>
<td>✅</td>
<td>✅</td>
</tr>
<tr>
<td>5. Service Delivery/Care (interaction at patient level)</td>
<td>✅</td>
<td>✅</td>
</tr>
<tr>
<td>6. Workforce</td>
<td>✅</td>
<td>✅</td>
</tr>
<tr>
<td>7. Health Information Systems</td>
<td>✅</td>
<td>✅</td>
</tr>
<tr>
<td>8. Prevention</td>
<td>✅</td>
<td>✅</td>
</tr>
<tr>
<td>9. Community/environmental connections</td>
<td>✅</td>
<td>✅</td>
</tr>
</tbody>
</table>

A review of the aforementioned models points to some clear areas of overlap. Financing, availability of medical products, and governance align with “resources and policies” in the CCM (although the CCM fails to speak specifically about finance, it is presumed). The WHO’s definition of workforce seems to overlap with the decision support and delivery system components. Information systems exist as such in both models. The WHO Health System Building Blocks model and other health system models fail to account for CCM’s “self management” component, which could be characterized as health education/literacy and psychosocial support, the latter of which begins to meld with community resources in the CCM.

Both the WHO and the CCM models fail to take prevention into account, which cannot be divorced from treatment and care from a health system perspective, keeping the goals of the system in mind. However, the ICCC model and other variations of the CCM do incorporate prevention and community engagement/involvement to a greater degree. Service delivery (i.e. interaction at the patient level) is common across all models. Health sector infrastructure is
specifically mentioned in the WHO Building Blocks model as a part of “service delivery.” This issue is not directly mentioned in the ICCCF model, which is ironic, considering the model was created for use in the developing world, where infrastructure is almost always an important factor in health system planning and reform.

All of the models address workforce issue in one way or another: the CCM calls it “decision support,” while the ICCCF describes it as “organized and equipped health care teams, the WHO health system models name it plainly as workforce, while Roemer lumps it together with aspects of the delivery system. The ICCCF discussed above addresses the issues of workforce, information systems, financing, patient literacy/education, and leadership, but it does not clarify aspects of service delivery and only alludes to the need for medical products by describing teams as needing to be “well-equipped.” Health information systems is common to all the chronic care models, but is only found in the WHO’s model for health systems.

Two components appear in the chronic disease models that are not directly addressed in any of the health system models. These are prevention and community resources. Disease prevention is frequently defined as any activity intended to reduce the morbidity and mortality of a disease and activities can be categorized as primary, secondary, or tertiary prevention. Disease prevention is frequently implicitly linked to “health promotion” activities. The WHO defined health promotion through the Ottawa Charter in 1986 as:

“Health promotion is the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy life-styles to well-being.” [40]

This definition is aligned with the variations of the socio-ecological model or social determinants of health models [32, 41], in which interventions for disease prevention and health promotion can and should span the continuum of environments that an individual is exposed to, from direct interactions with health care providers, to broad health, education, labor, and agricultural policies that would promote and support healthy lifestyles and choices. One of the main differences between these two models is that the socio-ecological model places the individual at the center of multiple levels of factors that may impact his/her health, as opposed to other models that are more linear in nature. Some of these linear models fail to account for the connectivity between the various factors that impact and individual’s health.

Community resources in the chronic disease models mentioned previously described seem to be more vaguely characterized as resources in a separate sector [the private sector] that are complementary to traditional medical resources. These can include psycho-social support networks, such as mental health, nutritional, or occupational counseling. These could be considered by some to be synonymous with self-management support.
A Proposed Model for Examining Health System Response to Chronic Disease

Understanding how a health system responds to the needs of an individual with a chronic disease is a complex undertaking. Taking into account the strengths and weakness of the various aforementioned models, the author proposes a new model that may be better suited to examining how a health system responds to chronic disease. This model places the individual at the center of an environment of several factors placed in concentric circles extending out from the individual that contribute to his/her health. The factors, ranging from macro to micro include: financing and expenditures; policy, including prevention policy; service delivery/care, which is shaped by the interaction of workforce, medical products, self-management support; and health information technology, which cuts across all levels of influence. See Figure 6. In this model, macro factors are financing and policy (in yellow), and micro factors (in orange) include those within the sphere of service delivery/care including workforce, medical products, and self-management support. Health information technology is simultaneously micro and macro, due to its importance in both spheres.

Figure 6: Proposed Model for Examining Health System Response to Chronic Disease

Financing in this context is defined as the mechanism by which funds are identified, raised, entered, and allocated for health sector activities. Like the Roberts et al definition, payment (how the money is actually spent) is defined as expenditure. Finance and Expenditure share a category. Policy encompasses the organization of the health care system, payment system, monitoring and regulation, and the guiding principles resulting in the prioritization of health care issues and programs. Service delivery/care refers to the interface and interaction that occurs at the patient level. This includes the orientation of the care (practice structure), as well as the subcomponents of 1) workforce, 2) medical products (pharmaceutical products and other medical devices/tools), and 3) self-management support (patient/family education, psychosocial support, including complimentary resources in the “community”).
Effective communication within this sphere is critical between all elements, particularly with the patient him/herself. This communication can and should be facilitated by health information technology. The model, like many of the versions of the chronic care model, presupposes the availability of and connectivity with acute care. It does not offer criteria to evaluate acute care related to chronic care, but rather asks if the linkage exists and how it functions as a component of coordinated care at the service delivery/care level.

Measuring how well a health system responds to the needs of an individual with a chronic disease is slightly more complex. Each factor or component can be evaluated using a number of process indicators, both qualitative and quantitative in nature. These are described in Table 6 and are intended to be population-level indicators.

**Table 6: Process Measures to Evaluate Health System Response to Chronic Disease:**

<table>
<thead>
<tr>
<th>Financing and Expenditure</th>
<th>Policy</th>
<th>Service Delivery</th>
<th>Medical Products</th>
<th>Self-Management Support</th>
<th>Workforce</th>
</tr>
</thead>
<tbody>
<tr>
<td>Source of funding and process for allocation</td>
<td>National treatment guidelines/protocols</td>
<td>Access to care</td>
<td>Availability of pharmaceutical products</td>
<td>Patient/family education programs</td>
<td></td>
</tr>
<tr>
<td>% private expenditure</td>
<td>Monitoring processes in place (disease status, adherence to protocols)</td>
<td>Adherence to treatment guidelines</td>
<td>Availability of monitoring tools</td>
<td>Psycho-social support</td>
<td></td>
</tr>
<tr>
<td>Expenditure for disease per person at national level</td>
<td>Prevention programs in place</td>
<td>% of patients on recommended treatment/therapy</td>
<td>Cost of pharmaceuticals and monitoring tools to patient</td>
<td>Patients involved in decision-making</td>
<td></td>
</tr>
<tr>
<td>% out of pocket expenditure</td>
<td>Incentive system in place to promote prevention</td>
<td>Coordinated care (incl. linkage to acute care)</td>
<td>Materials/guidelines available to patients</td>
<td>Use of information for care management</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Incentive system in place to promote treatment</td>
<td>Regular patient monitoring/testing</td>
<td></td>
<td>Feedback of performance data</td>
<td></td>
</tr>
<tr>
<td></td>
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</tbody>
</table>

However, the ultimate goal of a health system is to improve health. Using the WHO framework for health system performance, additional outcome indicators examining overall health status, responsiveness and financial protection should be utilized in the evaluation. Health status should be broken into additional disease-specific indicators, when relevant. At the population level, health status can be evaluated using disease prevalence incidence. Indicators at the individual level, which may better reflect what is happening at the service delivery/care level can and should be more specific to the chronic disease context. For example, for a person with diabetes, individual level outcome measures would include HbA1c, daily trends in blood glucose levels through the use of self-monitoring tools, and possibly blood pressure. For HIV/AIDS, this could include CD4 counts and viral load testing, among other indicators.
Some of these could be aggregated to the population level to give an overall picture of good health outcomes, such as percentage of patients with an LDL test that was below 130 mg/dL, percentage patients with an HbA1c test in 12 months that was below 7%, percentage of patients with a CD4 count above 200 or 350 cells per cubic millimeter. Adherence to treatment could also be considered an outcome measure, as it is an outcome of the patient’s interaction with the health system, although many might argue it would be more process oriented and/or unfair to put the burden of adherence entirely on the system. This type of data gathered for subsets of the national population are still relevant and could even, in some cases, serve as a proxy for the population at large. Proposed health indicators for diabetes and HIV/AIDS are listed in Table 7.

Table 7: Proposed Disease Specific Indicators of Improved Health

<table>
<thead>
<tr>
<th></th>
<th>Diabetes</th>
<th>HIV/AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Population level</strong></td>
<td>Prevalence</td>
<td>Prevalence</td>
</tr>
<tr>
<td></td>
<td>Incidence</td>
<td>Incidence</td>
</tr>
<tr>
<td><strong>Aggregated individual indicators</strong></td>
<td>% of patients with LDL below 130 mg/dL</td>
<td>% of patients with a CD4 count above 200</td>
</tr>
<tr>
<td></td>
<td>% of patients with HbA1C test in 12 months that was below 7%</td>
<td>% of patients with a CD4 count above 350</td>
</tr>
</tbody>
</table>

Responsiveness in the WHO Study was measured through a specific key informant survey. However, in the absence of more recent sampling using that survey, patient satisfaction surveys could serve as a proxy measure for responsiveness if they focus on respect for persons and client orientation. A financial protection indicator is the ratio of total health contribution to total non-food spending. The additional measure of health system efficiency could be considered, where data are available; nonetheless, the calculations involved in this measure are complex and may be subject to misinterpretation.

**Discussion**

The proposed model recognizes that the financing and policy environment plays an overriding role in the health system response to chronic disease. Chronic disease, by definition, means an ongoing relationship with the health care system which carries with it significant cost. These costs necessitate fundamental reexamination in health system financing, which has traditionally been oriented towards payment for acute care. A strong funding base is critical for health systems facing a significant chronic disease burden. Health policy is closely linked to financing by helping to reduce costs through disease prevention (at all levels), reimbursement systems for payers and incentive systems for patients, providers, and payers. Policy also has the power to mandate monitoring and ensure compliance to achieve maximum system performance.

The role of prevention cannot be understated in the policy environment. If systems are to transform themselves from an acute care model of only “treating” disease into one that prevents and provides ongoing and continuous patient monitoring, support, and medical treatment, then prevention would seemingly fit into all components of the model, with dramatic implications: Providers would need to be reimbursed for preventive consultations and interventions, and systems need to generate the resources to finance them. Leaders at all levels need to embrace this philosophical change, and the policies they generate need to reflect this transformation.
Providers need to be educated to be able to talk to and work with patients on prevention, and provider teams need to be reoriented to make this feasible. Information systems would track patients while they are well, as well as once they become sick. Finally, individuals would be better educated about their health, starting from their kindergarten years to their golden years, with greater understanding of how their behavior affects their health and their wallets – reaping the rewards of healthier choices by being an active participant in managing their own well-being.

The model then moves to the more micro level of the service delivery and care system. This is not truly “micro,” but rather it begins to describe the sphere that individuals most directly interact with. This sphere or component addresses access to care and the orientation of care, in keeping with the Nolte model discussed earlier health care continuum model and the various iterations of the Chronic Care Model. It also serves as the appropriate level for monitoring and evaluation because it interacts directly with patients and with higher level authorities (i.e. governments). The functioning of this level, though, is dependent upon its various highly interactive subcomponents: the medical products, workforce, and self-management support. These three elements represent the three most proximal factors that affect a person with chronic disease. In a way, these elements speak to the basics of healthcare: the medical goods, the health care provider(s), and the patient’s own actions. That is not to say that these are the only interacting elements at this level, but rather that this model holds them as most relevant when evaluating the response to chronic disease. All of these pieces are connected by an overriding need for effective coordination and communication, including with acute care, when needed.

At the “service delivery/care level” effective communication is of the utmost importance. Bodenheimer et al have presented different scenarios for managing the care for patients with chronic diseases. These include 1) the specialist physician provides most care for the patient; 2) the primary care physician assumes responsibility for most chronic care patients; and 3) a multidisciplinary team in primary care provides care for the patient and coordinates referrals to specialty/ancillary services outside [42]. Bodenheimer advocates for a primary care multidisciplinary team approach. Primary care physicians can take the patients full range of conditions into account, something that may not be considered by a specialist seeing a patient for only one condition. Furthermore, care provided by primary care physicians is often less expensive than specialist care. However, Bodenheimer also points out that scenario of the primary care physician alone has drawbacks, including patient lack of participation in clinical decision making and general lack of understanding the physician. Hence the utility in a team approach to improve communication with the patient and coordination with specialists when needed. The team scenario may help alleviate time pressures on primary care physicians, who would otherwise not have time to manage all patients with chronic diseases unless he/she reduced the overall patient load (and there were other primary care doctors available to provide care). Involving more players in patient care necessitates effective communication with all providers and the patient.

Effective communication upstream (ie. from the patient to the provider(s) to the system) can take transpire in the form of health information technology. This cross-cutting element represents data provided directly from the patient (e.g. a blood glucose measurement) that can be transmitted to all health care providers touching that patient’s life to complex epidemiological
surveillance networks that an alert policy makers to populations that may be at particular risk and in need of greater intervention.

Every single component in the model plays a role in determining the overall health outcome for the individual with a chronic disease. This is demonstrated by keeping the patient/individual at the center of the model. This particular approach differs from some of the chronic care models that focus to a great extent on provider-patient interactions. This model does not deny the importance of that relationship, but rather, recognizes that it is only one piece of the entire health system puzzle. On the flip side, many of the health system models fail to address these micro-components and seemingly speak to each component without noting its interconnection with the others. No other model to date brings all the aspects of health systems and chronic care together in this way.

Applying this model and the proposed indicators to the evaluation of health system responses to chronic disease will be the real test of its utility. This paper presents some possible indicators to evaluate how a health system is responding. However, these indicators may not be the most helpful; other useful indicators may be uncovered as researchers undertake the process of examining health systems. The availability of data will, in many cases, drive the selection of indicators. Upper-income countries with vast and regular data may be easier to profile and evaluate than low- or middle-income countries lacking similar data.

Next Steps

The next section of this project tests the proposed model and attempts to answer the following research questions:

1. What does the burden of HIV/AIDS and diabetes look like in Mexico and Brazil?
2. How have recent public health system reforms responded to HIV/AIDS and to diabetes in Mexico and Brazil?
3. What lessons and policy recommendations can be drawn from the experiences in these two countries that will be of use to other countries, specifically low and middle-income countries?

Methodology

The proposed framework is critical to the development of the subsequent analysis which are case studies analyzing the public health responses of the Governments of Mexico and Brazil to their respective epidemics of HIV/AIDS and diabetes. To achieve this, an extensive literature review was undertaken for both case studies. It encompassed aspects of health system reform, disease epidemiology for both HIV/AIDS and diabetes, current policies and practices, health finance mechanisms, health expenditures, and other elements identified in the aforementioned framework. In addition to reviewing documents from the World Health Organization (WHO), International Diabetes Federation (IDF), and the Joint United Nations Program on AIDS (UNAIDS), I also conducted extensive research into the “grey literature” of government documents available through the websites of the Secretary of Health of Mexico and the Ministry of Health of Brazil and their related links, where relevant.
I analyzed the quantitative secondary data in a comparative way, and did not undertake any advanced statistical analysis. This review helped construct the story of how the two diseases have affected the organization of the health systems.

Recognizing that the scientific literature and current public documents have their limitations in providing a complete portrait of the health system response, I recognized the need to interview experts in both countries. I developed an open-ended interview guide to provide some structure to the in-depth interviews with key informants. The guide included questions related to each of the components determined in the model: financing and expenditure, policy, service delivery, medical products, self management support, workforce, and information technology. The questions strictly related to how the health system processes related to these areas.

Given my extensive experience in both countries and with both diseases, I utilized existing contacts to identify key informants. I sought interviews with government officials at the federal and state levels with knowledge of programs related to HIV/AIDS and diabetes, as well as experts from non-governmental organizations and academia who were working on these diseases. I travelled through Mexico during two weeks in December 2009, and through Brazil for over two weeks in late February/early March 2010. I utilized “snowball” sampling methodology until I achieved saturation in data; i.e., when I no longer learned new information about the research topic and people were repeating the same information. This approach resulted meeting with 16 key informants in Mexico and 18 key informants in Brazil.

Each informant held expertise in certain areas, so it was not necessary to utilize the entire guide on any one informant. The interviews lasted on average less than sixty minutes and were conducted mostly in Spanish or a mixture of Spanish and Portuguese. A few interview transpired in English. This approach offered me the opportunity to probe issues that were not covered sufficiently in the public health literature or the “grey” literature of government documents and reports from international organizations. Furthermore, mixing both primary and secondary data contributed to strong construct validity of the findings.

Focusing on how the health systems have responded to the diseases, means I will be attempting to chronicle changes to the health system along the criteria developed in the conceptual framework in chapter 2. As such, the papers will then systematically describe and evaluate each of the components/elements of the health system critical to chronic care both prior to the reforms, as well as after the reforms. Critical issues, successful approaches, and obstacles/difficulties encountered will be summarized to provide policy recommendations.

The conclusion then revisits the conceptual framework through a discussion of its implementation in the case studies. Then it moves into a discussion of the issues that arise through comparison of the two cases. I then close the manuscript with a discussion of final recommendations and areas for future exploration.

**Human Subjects**

After reviewing the study protocol and interview instrument, the University of California’s Human Subjects Institutional Review Board deemed that the interviews of key informants...
regarding the health system processes related to HIV/AIDS and diabetes mellitus did not constitute human subjects research.

**Conclusions**

Addressing chronic diseases means directly or indirectly addressing the health systems in which they are prevented, diagnosed, and treated. Given the vast amount of resources being utilized to address these diseases, a close examination of the impact on health systems is warranted. Are the diseases approached in a silo-ed manner? Are they approached in an integrated way? What are the outcomes for the system (i.e. Do expenditures rise or fall? Are the systems operating more efficiently?)? What are the outcomes for the patient (i.e. do they remain healthy longer, with shorter, less frequent periods of acute illness?)?

Frameworks and models are useful not only for evaluating existing systems but also as policy tools to focus on priorities. In short, this paper offers a starting point to take a fresh look at national health systems in the context of an ever-growing burden of chronic disease. It is hoped that others will test the proposed model to not only evaluate how health systems are or are not working, but also to offer a vision of how they might work more effectively.
References


**Introduction to Mexico**

The United Mexican States, most often referred to as Mexico, borders the United States of America on the north and Belize and Guatemala to the south. Its nearly 2 million square kilometers are roughly three times the size of Texas. Divided into thirty-one states and a Federal District, Mexico is a federal republic. It is the world’s 11th most populous country with a population estimated to be about 111 million, making it second largest in Latin America to Brazil [1]. It is estimated that approximately 76% of the population lives in urban areas, with about 22 million people living in the area around Mexico City (the Federal District). Mexico’s population is largely mestizo (Amerindian-Spanish) (60%), with the Amerindian population accounting for approximately 30%, whites accounting for 9% and others, 1% [2]. Much of the Amerindian population resides in the southern states, which are poorer and less developed than the northern industrial states, prompting internal migration.

**Economics and Development**

Mexico has experienced unprecedented economic stability since its 1994 crisis, contributing to overall growth and development, although significant income gaps remain between urban and rural populations. Mexico has a free market economy, and trade with the United States and Canada has nearly tripled since the implementation of the North American Free Trade Agreement in 1994 [3]. Mexico’s economy is closely linked with that of the United States, with exports to the U.S. representing nearly a quarter of the Gross Domestic Product (GDP), and remittances from Mexicans living in the U.S. also comprising an important part of the economy [1]. By 2008, the GDP was estimated to be $1.143 billion, although this reflects a decrease in growth over recent years. Real GDP grew by 4.8% in 2006, 3.3% in 2007, and 1.4% in 2008, and officials in Mexico project the economy could contract about 5% during 2009.

Mexico ranked 52nd in the classification of countries in the Human Development Report 2007/2008, with an overall value of 0.829, demonstrating sustained improvement over the past 3 decades, and an adult literacy rate of 91.6% [4]. The gross national income per capita (Atlas Method) in 2008 was $9,980 [5]. However, the richest 10% of the population receive 46% of national income, while the poorest 10% only receive 1.6%, resulting in a Gini index score of 46.1 and demonstrating high inequality in income distribution nation-wide [4].

**General Mortality and Morbidity**

Marked by declining fertility rates, rising life expectancies, decreases in infectious disease rates, and rapidly increasing rates of chronic disease, Mexico has been undergoing a demographic and epidemiological transition over the past few decades. The Total Fertility Rate has dropped significantly from 6.5 births per woman between 1970-1975 to 2.4 between 2000-2005, and to 2.1 by 2007 [4, 5]. Life expectancy in Mexico has increased from 71.47 years in 1991 to 75 years in 2007, with women living on average longer than men [6]. With the exception of certain conditions around the perinatal period, the leading causes of death for both sexes and all age groups are all chronic diseases. See Table 1 below. A more recent study in 2007 demonstrated that diabetes also remained the leading cause of death for both men and women of all ages [7].
Table 1: Leading causes of mortality (all ages, both sexes) in 2005

<table>
<thead>
<tr>
<th>Cause</th>
<th>Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes Mellitus</td>
<td>67,090</td>
</tr>
<tr>
<td>Ischemic heart diseases</td>
<td>53,188</td>
</tr>
<tr>
<td>Cirrhosis and other chronic diseases of the liver</td>
<td>27,566</td>
</tr>
<tr>
<td>Cerebrovascular diseases</td>
<td>27,370</td>
</tr>
<tr>
<td>Chronic obstructive pulmonary disease</td>
<td>20,253</td>
</tr>
<tr>
<td>Perinatal conditions</td>
<td>16,448</td>
</tr>
<tr>
<td>Motor vehicle crashes</td>
<td>15,742</td>
</tr>
<tr>
<td>Acute lower respiratory infections</td>
<td>14,979</td>
</tr>
<tr>
<td>Hypertensive disease</td>
<td>12,876</td>
</tr>
<tr>
<td>Nephritis and Nephrosis</td>
<td>11,397</td>
</tr>
</tbody>
</table>

Source: Secretaría de Salud de México [8]

Diabetes Epidemiology

Diabetes has been the leading cause of death in Mexico since 2005; 97% of all new registered cases are type 2 diabetes [9]. The disease has steadily increased in the country since the early 1990s, when estimated prevalence rates ranged from 4.6% to 8.1% [10, 11]. Mortality due to diabetes has increased on average 6% over the past seven years [9]. A national health survey in Mexico in 2000 revealed a prevalence of 7.5% in adults ages 20 years and older, with men having a slightly lower prevalence than women [12]. Recent studies have estimated the diabetes prevalence rate to be around 10.6 (as of 2007), which amounts to more than 6.1 million people [13, 14].

Figure 1. Prevalence of Diabetes Mellitus from Previous Medical Diagnosis, by Mexican State per 2005 ENSANUT

Source: Secretaría de Salud de México 2006

However, some experts believe these studies have underestimated the diabetes prevalence and that it could be anywhere from 12 to 22% [11, 15]. Many people with diabetes are not aware of their condition because they may have no symptoms, or are not diagnosed once symptoms appear. Research points to higher prevalence in urban areas, particularly in the northern states and in Mexico City. One recent study of 150,000 men and women in Mexico City suggested a
prevalence of approximately 13.7% in 2004 [16]. A binational study conducted by state and national government officials in the United States and Mexico, in coordination with the Pan American Health Organization, in 2001-2002 in the U.S.-Mexico border region (defined as 100 kilometers north and south along the length of the border, with an estimated population of 12 million [17]) found diabetes prevalence to be 15.7%, or approximately 1.2 million people living with diabetes [18]. The 2005 National Health and Nutrition Survey (ENSANUT) confirmed this finding, and also found higher rates in some of the coastal areas. See Figure 1.

The diabetes burden not only varies by geographic region and gender, but also by education and income [11, 19]. Those with the least amount of education have typically been found to have the highest rates of diabetes. Similarly, those in the lowest income quintiles typically bear the greatest burden of the disease. Mexico does not typically break down data by racial/ethnic groups, although it should be restated that Mexico has a large indigenous or Native American population. The Native Americans living along the American side of the U.S.-Mexico border have some of the highest rates of diabetes in the world, and it could be presumed that if data were collected on these tribal populations in Mexico, the rates would be similar.

The burden of diabetes in Mexico is expected to worsen over the coming decade. It is estimated that approximately an additional 8% of Mexicans have impaired glucose tolerance, putting them at increased risk for developing type 2 diabetes [13]. The region of the U.S. Mexico border has an ever higher prevalence of impaired glucose tolerance, estimated to be about 14% [18]. Consequently, it is projected that by 2025, 12.4% of Mexicans (some 10.8 million people) will be living with diabetes, and 8.8% will have impaired glucose tolerance [13]. This projection does not take the growing obesity trend in Mexico into account, which, unless addressed will likely exacerbate the problem and increase the prevalence further. Overweight and obesity, as well as diabetes, are becoming rapidly more common among children and adolescents [9]. A 2006 national survey found that approximately 66.7% of adult males and 71.9% of adult females were overweight; of these, 24.2% of adult males and 34.5% of adult females in Mexico are obese [20]. The border diabetes study also found that an alarming 75% of the adult population in the region are overweight or obese.

**HIV/AIDS Epidemiology**

AIDS was first diagnosed in Mexico in 1983 and continued to rise during the following two decades. However, many cases went undiagnosed or un-notified due to surveillance problems within the country, a problem that has only been remedied in recent years. By 2005, HIV/AIDS was the 17th ranking cause of death in Mexico [8]. As of 2007, it was estimated that there were 200,000 cases of HIV/AIDS, with a population prevalence of 0.3%, and by 2009 there were 220,000 cases and an estimated prevalence of 0.37% [21, 22]. While this rate may seem low, Mexico ranks third in the region of the Americas in terms of number of registered cases, after the United States and Brazil.

HIV in Mexico is frequently described as a concentrated epidemic, affecting specific most-at-risk populations, as opposed to a generalized epidemic in the population at large. By 2003, it was determined that most of AIDS cases were found in males (approximately 85%) [23].
although that number dropped to 83% by 2007 [24]. While in the early days of the epidemic, transmission was largely limited to men who have sex with men (MSM) or injecting drug users (IDU), a growing number of women are being infected through heterosexual sex. Figure 2 describes the distribution of persons living with HIV. Figure 3 describes the prevalence by population group. According to the United States Agency for International Development (USAID), heterosexual transmission is increasing, particularly in southern states of Mexico [25]. Unlike the epidemiology of AIDS in parts of Africa, this is not a self-sustaining heterosexual epidemic, but rather an epidemic among the core MSM and IDU groups that spills over to heterosexual infections. Multiple concurrent sexual partners is not normative in Mexico, which is a contributing factor to high prevalence rates in other countries. Male circumcision, which has been shown to reduce transmission, is also not normative in Mexico [26].

Geographically, the greatest disease burden is in the Federal District (accumulated incidence rate of 236.9 cases per 100,000 population), followed by the border state of Baja California (169.6), with the states of Yucatán (153.2), Morelos (150.2), Jalisco (143.2), Veracruz (142.1), and Quintana Roo (132.2) (all located in the southern portion of the country) also having above average rates [24]. Many of these states contain significant port cities or tourist destinations. The epidemic is largely urban, with only about 7% of cases estimated to be found in rural areas [23, 24]. It is important to note, however, that means of transmission vary between these two areas: in rural areas, heterosexual transmission comprises roughly 43% of cases, compared to 47.4% of cases related to MSM; in urban areas, heterosexual transmission represents 28.2% of cases and 63% are related to MSM [24].

Source: CENSIDA, 2009

**Mexico’s Health System and Reforms**
Health care coverage in Mexico is highly segmented and provided through three main components: a “social security” system for workers in the public sector, a public sector for those unemployed or working in the informal sector, and a private sector [27]. See Figure 4. For those formally employed, insurance is offered as part of a package of employee benefits, also known as “social security” benefits for those employed in the formal sector. The social security institutions covered approximately 56.4 million workers or roughly half the national population in 2005. The *Instituto Mexicano del Seguro Social* (IMSS), or Mexican Institute for Social Security, is the largest insurer, covering about 79% of the formal worker population. IMSS also
covers retirees and their families. Additionally, the Instituto de Seguridad y Servicios Sociales de los Trabajadores del Estado (ISSSTE), or the Insurance and Social Service Institute for State Workers, covering about 19% [28]. Other public social security systems for the military and other government workers exist but cover much smaller segments of the population. Informal workers, the rural uninsured, and the unemployed accounted for about 45 million people in 2005 and receive their care through the separate entity of the Secretaría de Salud (SSA), or Secretariat of Health and its program “Seguro Popular” [28]. Only about 4% of the population receives its care through the private sector. Each health system has its own financing mechanisms, service delivery structure, and network of clinics and hospitals [29]. This paper will focus on IMSS and SSA, as these two systems represent the largest portion of the public health system.

**Figure 4: Organization of Mexican Health System**

![Organization of Mexican Health System](source)

Source: Frenk et al 2003

The Secretariat of Health (SSA) and the Mexican Institute for Social Security (IMSS) date back to 1943, formalizing a schism between the workers in the formal sector and the poor or those working in the informal sector [29] that is reflected in separate health care financing and health service delivery for the two units. This health system model failed to reach many of the rural poor by the late 1960s, as the country was beginning its epidemiological transition, so a set of reforms began by the late 1970s. Concomitantly, Mexico was facing a growing economic crisis, compounded with high levels of spending on curative care that only benefitted a few. This culminated in the passage of a constitutional reform in 1983, which established “the right of every person to the protection of their health” (ibid). However, due to the passage of this bright promise did not make it so, and many have blamed the structure of the system as the obstacle to its achievement.
Passage of the reform did bring about some important changes through the utilization of the primary health care model and a decentralization of services. This included an emphasis on oral rehydration, immunization, improved access to safe drinking water, and improved reproductive and family health services. These activities had a significant impact on health as evidenced by huge declines in mortality and diarrheal disease and an increase in immunization rates [29].

Reforms in the 1980s also included an aggressive approach to curbing the emerging HIV/AIDS epidemic, which was spreading rapidly, in no small part due to lack of quality standards around blood transfusions. The reforms specifically included the creation of a network of HIV detection labs, as well as the formation of an AIDS Prevention Committee (ibid). Nonetheless, these improvements did not reach all sectors of the population equally, and disparities persisted in some of the poorest areas.

The 1990s brought recognition that 1) financing needed to be separated from service provision, 2) focus needed to be placed on cost-effective health interventions, 3) quality of care needed improvement, and 4) greater citizen participation was needed [29]. By this time, decentralization of the SSA was complete and IMSS had made improvements to its financing and quality of care. The Social Security Law was passed in 1995, changing both service structure and financial structure for IMSS and the other social security institutions [27]. IMSS had divided its coverage into 35 “delegations” which were clustered into four regions [28]. Each of the regions has organizational responsibility for strategic planning and oversight of activities, although it reports to IMSS Headquarters.

IMSS also shifted its financing so that the financial burden shifted from payroll taxes to public financing through general revenue collection [27]. Employees and employers were not entirely “off the hook.” Under the revised scheme, there are three sources of financing for the IMSS system: the Federal Government through a fixed contribution, the private employer through a tax, and the employee through a progressive proportion of wage deducted from payroll [30].

The positive atmosphere for health sector reform and the recognition of need for extended health care coverage resulted in another further action. SSA implemented the “Program of Extension of Coverage,” which provided basic health interventions [29]. Among the packages intervention was a program for the prevention and control of hypertension and diabetes. See Table 2.

| 1. Basic household sanitary measures | 2. Family Planning |
| 5. Immunization | 6. Treatment of diarrhea at the household level |
| 7. Treatment of common parasitic diseases | 8. Treatment of acute respiratory infections |

Source: Frenk et al 2003
Furthermore, the Programa de Educación, Salud, y Alimentación (Program of Education, Health and Nutrition, PROGRESA) program was introduced in 1998 with the goal of incentivizing adherence to education, health and nutrition interventions through cash subsidies to poor people. PROGRESA has been evaluated extensively and hailed as an innovative and effective approach to improve child and adult health, school attendance, and nutrition.

However, many challenges remained in extending care to Mexico’s most underserved populations. Frenk et al identified five financial imbalances that were identified as constraints preventing the SSA from responding to the health care needs posed by the emerging epidemiological profile [31]. These included: 1) low level of overall health spending (5.6% of the GDP or about $350/person in 2000 compared to the Latin American average of 7%); 2) predominance of out-of-pocket spending (in 1999 greater than 52% of all health expenditures were private, reflecting lack of insurance among the poor, since only 4% had private insurance [32]); 3) unfair allocations of public resources between the insured and uninsured among the states; 4) inequitable contributions of states to finance health care; and 5) chronic under-investments in health infrastructure [31].

To address these challenges, Dr. Julio Frenk, then Secretary of Health, developed the National Health Plan 2001-2006, based on the principles delineated by the WHO of equity, quality and financial protection [33]. Although the constitution theoretically provided the social right to health protection, the reality was that those who did not receive their health insurance through formal employment did not enjoy this benefit. Dr. Frenk worked to pass the 2003 reform of the General Health Law (entering into force January 1, 2004), which was intended to reorganize the health system through the horizontal integration of stewardship, financing, and service delivery.

The reform aimed to provide universal health insurance through the establishment of Social Protection in Health (SPH), which explicitly separated financing for personal and non-personal health services. The objectives were to 1) generate a gradual, predictable, financially sustainable, and fiscally responsible mechanism to increase public spending in health; 2) to stimulate greater allocational efficiency by protecting spending for public health interventions that are cost-effective but tend to be underfunded; 3) to protect families from excessive health spending by offering a collective mechanism that fairly manages the risks associated with paying for personal health services; and 4) to transform the incentives in the system by moving from supply-side subsidies to demand-side subsidies in order to promote quality, efficiency and responsiveness to users [30]. Non-personal services are defined as health related public goods such as stewardship functions (regulatory issues related to environment, sanitation, food, health technology, and pharmaceuticals; epidemiological surveillance; strategic planning; health information systems; human resources; research), and community-based health promotion/disease prevention activities [31].

Non-catastrophic personal health services would be funded through a new public insurance scheme through SSA that became known as “Seguro Popular” (Popular [Health] Insurance), and while high-cost, catastrophic personal health services would be funded through a newly formed “Fund for Protection against Catastrophic Expenditures.” The reform defined a set of essential primary and secondary level health interventions that would be provided in ambulatory settings and general hospitals. The number of interventions covered is scaling-up over the
implementation period. The first “Catalogue of Universal Health Services” published in 2002 included 78 health interventions [34]. By the first half of 2005, 154 interventions were covered, and by the end of 2006, 249 interventions were covered, and by 2008, 266 were covered [30, 31, 34]. Health facilities are accredited to participate in Seguro Popular based on their ability to provide these interventions. See Figure 5.

High-cost, catastrophic conditions and diseases are defined by the General Health Council, which also determines which interventions will be covered by the Fund for Protection against Catastrophic Expenditures. They currently include cancer, cardiovascular problems, cerebrovascular disease, severe injury, long term rehabilitation, HIV/AIDS, neonatal intensive care, organ transplant, and renal dialysis[30]. As of 2006, 17 interventions were covered by the Catastrophic Fund, and by July 2009 49 interventions were covered [35].

**Figure 5: Current Organization of Mexican Health System (Post-2004 Reforms).** Changes are found under the “Secretaría de Salud” section to reflect incorporation of Seguro Popular

Source: Programa Nacional de Salud 2007-2012; Por un México sano; Secretaría de Salud de México

It should be noted that in August 2003 the Government of Mexico made a commitment to provide universal access to anti-retroviral therapy (ART) for all people living with HIV/AIDS. Prior to this, only those eligible to receive care through IMSS had access to ART. As an interim step, a special fund known as FONSIDA was created in 1997 with government donations to provide free treatment to those who did not have care through IMSS [36]. However, this fund ceased operations in 2000 when the budget for HIV/AIDS therapy was incorporated into the Secretariat of Health. The creation of the Fund for Protection of Catastrophic Expenditures then effectively carved out HIV/AIDS treatment again, but kept it within the Secretariat.

The source of funding for Seguro Popular within SSA is tripartite: the federal government, the state/federal governments in solidarity (i.e. as co-contributors), and the beneficiaries. The Federal Government contributes 15% of the mandatory minimum wage, which was equivalent to about $230 per year per family in 2005 [30]. The states pay the equivalent of half the federal
contribution (therefore the state contribution is equal for all states), drawing on their state revenues, and the federal government supplements the rest. On average the federal solidarity contribution is 1.5 times that of the state contribution, but is greater for poorer states (at the expense of wealthier states) in an effort to address the huge disparities among states. Lastly, the third component is a contribution from the beneficiaries in the form of pre-payment based on a sliding scale. Contribution is capped at 5% of disposable family income (defined by the SSA as total spending minus expenditures for basic needs), and families in the lowest two income deciles do not pay for the insurance but must adhere to the rules of Seguro Popular. Once funding is collected from the various sources, the allocation process is also divided between the states and the federal government. All funds collected from families are collected and maintained at the state level. See Figure 5.

The source of funding for the Catastrophic Fund is 8% of the federal social contribution plus the state/federal solidarity contribution [30]. However, an agreement with the tobacco industry was also signed in 2004 to provide funding for the Catastrophic Fund: Philip Morris and BAT, Mexico’s largest tobacco companies agreed to a $385 million donation by the end of December 2006 [28, 37]. This agreement was highly controversial and was not renewed.

The remaining 82% of the federal social contribution plus state/federal solidarity funds are allocated to the states to fund the essential package of health services described above. The funding for the states is driven primarily by enrollment/affiliation into Seguro Popular. As enrollment grows in a state, so does the amount of funding received. Enrollment for beneficiaries is voluntary, however, those who do not enroll by 2010, while still maintaining access to public providers, will have to pay on a fee for service basis at the point of delivery.

When an enrollee in Seguro Popular presents at a Seguro Popular Health Service Provider (i.e. public clinic or provider otherwise affiliated with the program and accredited by it), with a condition that is on the list of conditions covered by the Catastrophic Fund, the flow of funding is slightly different. Upon diagnosis, the provider is required to notify the National Commission for Social Protection in Health per the instructions provided in Operations Manuel for the Notification of Cases of Illness that Generate Catastrophic Expenditures [38]. This serves two purposes: 1) it allows the government to maintain an active disease registry for all illnesses covered by the Catastrophic Fund and 2) creates a billing system for providers offering care to people with such a condition.

The WHO estimated that in 2006, total health spending amounted to 6.6% of the GDP or about $62.6 billion (2009 dollars) [39]. This is an increase over the 2000 level of 5.6%. Government expenditure accounted for 44.2%, with private expenditure comprising the remaining 55.8%. Of the private expenditures on health, roughly 94% was comprised of out of pocket expenditures, with the remaining 6% coming from private pre-paid health plans. Per capita total expenditure on health (average exchange rate) increased from $327 in 2000 to $527 by 2006, with the government paying approximately $233 per capita (leaving the individual to cover the remaining $194). This means that individuals still pay a significant amount on health care.

In addition to changes in the financial structures of health care, the reforms instituted through the SPH included extension of infrastructure. Health services for those enrolled under Seguro
Popular are largely contracted with existing public providers from the various state-level ministries of health. However, it was recognized that for the vision of extending care to be fully realized, additional service providers and facilities would be needed. Funding was made available to the states for building new health units or hospitals based on the outcomes of a needs assessment. This assessment was intended to help under-served areas build the necessary capacity to serve the populations. For example, by 2006, nearly 1800 new health units were constructed, including four tertiary care regional hospitals in the least developed states of Chiapas, Oaxaca, and Tabasco [31]. A plan for examining needs for human resources in health was also developed, along with a plan to invest further in medical equipment.

**Examining Health System Responses**

Understanding how a health system responds to the needs of an individual with a chronic disease is a complex undertaking. The author proposes a new model that may be useful in examining how a health system responds to chronic disease. This model places the individual at the center of an environment of several factors placed in concentric circles extending out from the individual that contribute to his/her health. The factors, ranging from macro to micro include: financing; policy, including prevention policy; service delivery/care, which is shaped by the interaction of workforce, medical products, self-management support; and information technology, which cuts across all levels of influence. See Figure 6. In this model, macro factors are financing & expenditures and policy, and micro factors include those within the sphere of service delivery/care including workforce, medical products, and self-management support. Information technology is simultaneously micro and macro, due to its importance in both spheres.

**Figure 6: Proposed Model for Examining Health System Response to Chronic Disease**

Financing in this context is defined as the mechanism by which funds are identified, raised, entered, and allocated for health sector activities; how the money is spent is defined as
expenditure. Policy encompasses the organization of the health care system, payment system, monitoring and regulation, and the guiding principles resulting in the prioritization of health care issues and programs. Service delivery/care refers to the interface and interaction that occurs at the patient level. This includes the orientation of the care (practice structure), as well as the subcomponents of 1) workforce, 2) medical products (pharmaceutical products and other medical devices/tools), and 3) self-management support (patient/family education, psychosocial support, including complementary resources in the “community”). Table 3 provides process measures to evaluate the health system response to chronic diseases.

Table 3: Process Measures to Evaluate Health System Response to Chronic Disease:

<table>
<thead>
<tr>
<th>Financing and Expenditure</th>
<th>Policy</th>
<th>Service Delivery</th>
<th>Medical Products</th>
<th>Self-Management Support</th>
<th>Workforce</th>
</tr>
</thead>
<tbody>
<tr>
<td>Source of funding and process for allocation</td>
<td>National treatment guidelines/protocols</td>
<td>Access to care</td>
<td>Availability of pharmaceutical products</td>
<td>Patient/family education programs</td>
<td></td>
</tr>
<tr>
<td>% private expenditure</td>
<td>Monitoring processes in place (disease status, adherence to protocols)</td>
<td>Adherence to treatment guidelines</td>
<td>Availability of monitoring tools</td>
<td>Psycho-social support</td>
<td></td>
</tr>
<tr>
<td>Expenditure for disease per person at national level</td>
<td>Prevention programs in place</td>
<td>% of patients on recommended treatment/therapy</td>
<td>Cost of pharmaceuticals and monitoring tools to patient</td>
<td>Patients involved in decision-making</td>
<td></td>
</tr>
<tr>
<td>% out of pocket expenditure</td>
<td>Incentive system in place to promote prevention</td>
<td>Coordinated care (incl. linkage to acute care)</td>
<td>Cost of pharmaceuticals and monitoring tools to patient</td>
<td>Materials/guidelines available to patients</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Incentive system in place to promote treatment</td>
<td>Regular patient monitoring/testing</td>
<td></td>
<td>Use of information for care management</td>
<td></td>
</tr>
</tbody>
</table>

However, the ultimate goal of a health system is to improve health. Health status should be broken into additional disease-specific indicators, when relevant. Table 4 provides health outcome measures for diabetes and HIV/AIDS.

Table 4: Proposed Disease Specific Indicators of Improved Health

<table>
<thead>
<tr>
<th>Diabetes</th>
<th>HIV/AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Population level (General, specific at-risk populations)</strong></td>
<td><strong>Prevalence</strong></td>
</tr>
<tr>
<td>Prevalence</td>
<td>Prevalence</td>
</tr>
<tr>
<td>Incidence</td>
<td>Incidence</td>
</tr>
<tr>
<td><strong>Aggregated individual indicators</strong></td>
<td><strong>% of patients with a CD4 count above 200</strong></td>
</tr>
<tr>
<td>% of patients with LDL below 130 mg/dL</td>
<td>% of patients with a CD4 count above 350</td>
</tr>
<tr>
<td>% of patients with HbA1C test in 12 months that was below 7%</td>
<td></td>
</tr>
</tbody>
</table>
Health System Response to Diabetes

Financing and Expenditures

Determining how much Mexico is spending nationally as a result of its diabetes epidemic is a complicated undertaking. A number of attempts have been made to measure costs, and the results vary significantly. In 2007, the International Diabetes Federation estimated that Mexico spent approximately $3.4 billion to provide care and treatment for people living with diabetes [13]. This figure, which does include expenditures for public health programs as well as payments for medical care, was projected to increase to anywhere between $6 and $10.3 billion by the year 2025 (Ibid). As with many projections, this does not factor in the increasing rates of obesity among children and adults, which could drive these projections even higher. Average health expenditure per person with diabetes was $566 in Mexico (Ibid), far less than in neighboring countries to the north, where the average expenditure for an American with diabetes is $6231 and for a Canadian is $2581. However, among its Latin American neighbors, its expenditures are greater than the regional average of $265 per person.

Expenditures will vary based on how sick the patient is. Within the SSA (Secretariat of Health) system, the average expenditures per diabetic person per year vary from 3,000 pesos (~$230 USD) for a patient without any complications to 12,000 pesos (~$923 USD) with complications; 13,000 pesos (~$1,000 USD) with a comorbidity and 30,000 pesos (~$2308 USD) for patients requiring renal dialysis [40]. Similar estimates were not available from IMSS (ibid).

A recent study by Arredondo attempted to estimate the total direct and indirect costs for health care service providers attributable to diabetes in Mexico for the year 2010. They came up with a figure significantly lower than the estimates from the IDF. The study projected that about $90 million USD would be spent by the Ministry of Health (SSA/Seguro Popular) and $210 million would be spent by IMSS[15]. These costs exclude non-service related costs such as prevention campaigns. They also exclude the out-of-pocket costs faced by patients related to their care and treatment, which frequently are equal or exceed the amount spent by the health system. Out of pocket expenditures for persons in any health system were estimated to be $419 million nationwide. Some experts believe that out of pocket expenditures for people with diabetes have not decreased for people enrolled in Seguro Popular, compared to their expenditures previous to enrollment, despite the program’s efforts to reduce such burden [41]. It is interesting to note that the Secretariat of Health found in 2005 that the cost in Mexico of direct medical care for diabetes was equivalent to one third of the entire budget for IMSS (34%) [9, 42].

Seguro Popular provides care and treatment for people with type 1 and type 2 diabetes; it is not considered a condition leading to catastrophic expenditures. Consequently, the financing structure for diabetes is no different than any other condition covered under Seguro Popular as described above, with the exception of people with diabetes who develop end stage renal disease and require kidney dialysis. Kidney dialysis is covered by the Catastrophic Fund. The basic Seguro Popular package includes diabetes-related medications (metformin, glibenclamide (also known as glyburide), pravastatin) and insulin therapy in accordance with national standards of care. Further, medications as prescribed by specialists after a follow-up examination are also included. However, the basic monitoring tools of a blood glucose meter and test strips are not...
included in the package and can cost a significant amount to the patient in out-of-pocket expenditures. Furthermore, drug shortages (more common at the secondary level of care) within the system can mean patients must pay out of pocket to obtain medications in private pharmacies.

In IMSS, diabetes care and treatment is also included and is financed just like all other health conditions. IMSS maintains its own formulary, although it is very similar to that of Seguro Popular. It also does not include monitoring tools, and likewise, it is common for IMSS patients to spend a significant amount of money out of pocket to cover the costs when shortages occur. IMSS has been reported to run short of medications prescribed at the secondary level [40]. In both systems, if a patient needs to seek their medication in a private pharmacy there is no mechanism for reimbursement.

Policy

The health system reforms begun in 2000 fully recognized that Mexico had gone through the epidemiological transition and was now facing a dual burden of disease, with the hallmark evidence of a growing prevalence of chronic disease. Both the Secretariat of Health and the Social Security Institute have undertaken numerous steps to try to address the growing burden of diabetes in the Mexican population.

Mexico has a tradition of developing 5 year national health plans to delineate health priorities, objectives and strategies. In 2007, the Government of Mexico published the Sectorial Health Program for Health 2007-2010, in conjunction with the Secretariat of Health’s National Health Program 2007-2010 [43, 44]. Both reflect the overarching goals put in place by the National Plan for Development, which has four health specific objectives: improve the health conditions of the population; provide efficient health services to the population with quality, warmth and trust; reduce inequalities in health services through focused interventions on marginalized populations and vulnerable groups; and avoid impoverishing the population because of health care through universal medical insurance [43].

The Sectorial Program for Health represents the overarching goals and objectives for all branches of government providing healthcare, including IMSS and Seguro Popular. It lists one specific diabetes-related goal: “Reduce by 20% the rate of growth in diabetes mellitus-related mortality with respect to the trend observed during 1995-2006” (ibid). To attain this goal, the Sectorial Program delineates a specific line of action under the Strategy “Strengthen and integrate health promotion and disease prevention activities”: “Bolster an integrated policy for the prevention and control of overweight, obesity, diabetes mellitus, and cardiovascular and cerebrovascular conditions.”

The National Health Program 2007-2012, applies to all branches of government, given the reforms that placed stewardship for the entire national health system (SSA, IMSS, ISSSTE and the other institutions providing health care) defines two specific activities to achieve the aforementioned lines of action:

1. Consolidate an inter-institutional program for health promotion and prevention and control of overweight, obesity, cardiovascular risks and diabetes. The goal is to have
45% of the diabetic and hypertensive patients under control and create at least one mutual support group by type of condition in each public health center.

2. Consolidate inter-institutional coordination in the area of prevention, promotion and control of cardiovascular risk and diabetes. The goal is to increase detection of cardiovascular risk and diabetes in the population aged 20 years and older.

The Secretariat of Health also published a Diabetes Mellitus Specific Program of Action for 2007-2012, developed under the leadership the Subsecretariat of Prevention and Health Promotion [42]. Theoretically this document again could apply to all branches of government, however, its implementation plan only refers to organizations within the Secretariat. The Program describes the general objective as being the prevention, control and slowing of diabetes and its complications, as well as elevating the quality and quantity of years of healthy life in persons with the disease, through cost-effective interventions directed at the determinants and their consequences. The ten specific strategies (See Table 5) are further elaborated into lines of action. Annual goals are aimed at meeting the objective of reducing the rate of growth in mortality by 20%, described in the SESA. Intermediate impact, process and product goals are stated, along with twenty specific indicators to measure progress.

**Table 5: Strategies within the Diabetes Mellitus Specific Program of Action for 2007-2012**

<p>| | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>1.</td>
<td>Creation of institutional oversight mechanisms of the National Health System and other sectors to collectively address the environment and determinants of the diabetes epidemic in the Mexican population</td>
</tr>
<tr>
<td>2.</td>
<td>Push the state and municipal plans to support diabetes prevention and control activities</td>
</tr>
<tr>
<td>3.</td>
<td>Development of fiscal stimuli and policy modifications for the food industry to adopt healthy lifestyles with the participation of the various sectors and government mandates</td>
</tr>
<tr>
<td>4.</td>
<td>Strengthening of the infrastructure to manage diabetes and other chronic non-communicable diseases at the state and local level</td>
</tr>
<tr>
<td>5.</td>
<td>Development of competencies and skills of health professionals that participate in the treatment of people with diabetes and their families.</td>
</tr>
<tr>
<td>6.</td>
<td>Strengthening of the educational component (literacy in diabetes) directed at the community, persons living with diabetes, their families, and populations at risk.</td>
</tr>
<tr>
<td>7.</td>
<td>Incorporation of national and international cost-beneficial interventions based on best practice and scientific evidence</td>
</tr>
<tr>
<td>8.</td>
<td>Permanent accreditation of the National Network of Mutual Support Groups (Grupos de Ayuda Mutua known as GAM) to support the national goals of the program</td>
</tr>
<tr>
<td>10.</td>
<td>Development and strengthening of information systems, epidemiological surveillance and follow-up on decision making.</td>
</tr>
</tbody>
</table>

The 2000-2006 Diabetes Prevention and Control Program launched some important precursor steps to the achievement of the goals and strategies in the newer strategy. One of the key steps was the establishment of national guidelines for diagnosis criteria and management of detected cases. This was manifested through the launch of the National Health Card Program (Sistema de Cartillas Nacionales de Salud) [42]. The program designed, produced, and disseminated cards for five different population groups: children, adolescents, adult women, adult men, and older adults. The cards provide guidelines and a registry for many different health related conditions,
based on the specific population. Related to diabetes, they cover basic health education topics, blood glucose testing, cholesterol testing, and overweight/obesity. The cards recommend glucose testing every 3 years for adults age 45 and older with no risk factors, but every 3 years for adults age 20 and over who are overweight/obese or who have a family history of diabetes. For older adults, blood glucose testing is recommended every year. The cards for children and adolescents track nutritional status, but do not recommend any screening diabetes currently.

Another key development during this period was the development of Mutual Support Groups (Grupos de Ayuda Mutua or GAM). These will be discussed in further detail under the “Self-Management Section.” These groups were launched as a policy initiative to better control diabetes through direct interaction with people living with diabetes and their families to improve adherence to treatment and actively reduce the risk of complications. The accreditation of these groups has been critical to achievement of treatment goals, according to the Secretariat of Health [42]. There are no incentives for people to join these groups, and there are some anecdotal reports that these groups function less well in major urban centers with less “community feel” than those in smaller cities/towns [45].

IMSS has launched a number of very widely-recognized programs around diabetes awareness and prevention as well as other obesity-related conditions. PREVENIMSS is a health promotion and disease prevention program oriented by population age groups and largely focused on weight related conditions. DIABETIMSS is a recent program begun in 2008 within the organization that is focused on the development of special health teams for diabetes care. There are currently 429 Family Medicine Units within the IMSS system that have teams trained in diabetes care. Of the 1200 Family Medicine Units in the IMSS system, these 429 have at least 5 clinics working two shifts and see about 1.5 million enrollees [46].

IMSS has a link for patient-friendly diabetes information on its homepage, which provides some basic facts on the disease and treatment. In addition, they promote a major campaign to fight overweight, called “Vamos por más kilos,” (We’re going for more kilos [to lose]) a follow-on to their successful “Vamos por un millón de kilos” (We’re going [to lose] a million kilos!). The program targets not only overweight adolescents and adults (aged 13-60), but also targets people with already diagnosed diabetes or hypertension, through behavioral and dietary interventions. IMSS has not created any special incentives for patient participation.

In addition, IMSS has created a website for more detailed information regarding healthy nutrition. These programs and pages are easy to find and seem user-friendly for a broad internet savvy audience. Similar information cannot easily be found on the Secretary of Health’s website or the affiliated site for Seguro Popular. However, the Secretary of Health has developed a separate site called “todoensalud.org” (all about health). This site serves as a clearinghouse of patient-friendly health information on a number of issues, including diabetes, overweight/obesity, nutrition, cholesterol, and hypertension. The Secretariat of Health also launched a health promotion program/campaign known as the “Five Steps for Your Health to Live Better.” The five steps were provided in simple, understandable terms and widely promoted, including on the website (www.5pasos.org.mx): 1) move, 2) drink water, 3) eat vegetable and fruits, 4) measure yourself, and 5) share.
Both systems have clinical treatment guidelines for patients with diabetes. There was an attempt during the 2000s to consolidate the treatment guidelines into one national protocol, but efforts failed due to budget and coordination challenges. IMSS guidelines were updated as part of the DIABETIMSS program but have yet to be published. Dissemination of guidelines remains a challenge for both systems. Hard copies were published by SSA and made available on the web, but no consistent monitoring programs to ensure access to and adherence to the protocols were instituted at either organization. The guidelines are also geared only for physicians, and no guidelines were developed for other health professionals working with diabetic patients. Consequently, only physicians with access, time, and motivation are likely to utilize the guidelines.

Service Delivery/Care

Health services within both the SSA and the IMSS systems are tiered. Patients typically receive their care at a primary health care center, and their diabetes is managed at this level until/unless complications arise. At the primary care level patients receive care largely from internists who traditionally do not work in teams with other health professionals such as nurses, nutritionists or diabetes educators. However, both SSA and IMSS have made recent modifications in response to the growing burden of diabetes and chronic disease that is changing this paradigm.

As part of the plan to improve health infrastructure for the Social Protection in Health, the Secretariat of Health developed the model of Specialty Medical Units (Unidades de Especialidades Médicas or UNEMEs) as part of the integrated health response model. The UNEMEs are intended to be ambulatory health centers at the regional level, with special emphasis on conditions causing catastrophic health expenditures, such as oncology, hemodialysis, rehabilitation, HIV/AIDS and other sexually transmitted diseases, rehabilitation, ambulatory surgery, and laboratory diagnosis. However, UNEMEs were also to be established for three other specialties, including mental health, addictions, and overweight, cardiovascular risk and diabetes mellitus (originally named Sobrepeso, Riesgo Cardiovascular y Diabetes Mellitus or SoRiD, these Units were renamed UNEMEs for Chronic Disease) [47]. The Unit would be responsible for promotion, prevention, education, detection, adherence, treatment, and would refer and counter refer to primary, secondary and tertiary levels of care.

The first phase of the UNEMEs for Chronic Disease included the construction of 50 sites nationwide. The Federal Government supports the cost of building each one in the amount of 2,074,000 pesos or roughly $160,000. The budget for running each site comes from the States and averages 43,000,000 pesos (~$3.3 million USD) per year plus the cost of human resources to serve approximately 1,800 patients [40]. The UNEMEs are staffed by physicians, nutritionists, psychologists, social workers, and nursing personnel [42]. Care would be free of charge to those insured with Seguro Popular.

The Plan for the Prevention and Treatment of Chronic Diseases: Overweight, cardiovascular risk and diabetes mellitus, 2007-2010 also speaks to the creation of specialty UNEMES for Chronic Diseases. As of November 2009, 59 have been constructed nation-wide, and 45 are operating. Initial results indicate that on average 54% of the patients seen at the UNEMES for Chronic Diseases had their diabetes under control, evidenced by HbA1C results below 8% [46].
Coordination of care remains a challenge, despite the creation of UNEMES. If a patient requires care at a secondary or tertiary level, there is no system of shared patient information between the various levels. For example, a patient receiving a referral to a secondary health center would not have his/her health history and treatment history sent or shared to the referral site. This is not unique to the SSA; none of the health systems seems to have true portability of medical records among various levels of treatment or among sites if a patient moves.

The organization of health services by the Secretary of Health places a significant emphasis on primary and secondary care. Access to tertiary care can be difficult or untimely for many persons with severe diabetes complications. Specifically, if a person’s kidneys fail and he/she develops End-Stage Renal Disease, he/she would technically be provided with kidney dialysis at no cost. However, there are not enough dialysis centers in the public sector to meet the needs of this very sick population [40]. He/she may be put on a waiting list at a site, but may not receive the regular life-sustaining dialysis in time.

Within IMSS two different scenarios may play out, depending on whether a patient presents at a clinic where a DIABETIMSS team is trained or not. At clinics without a trained team, patients suspected to have diabetes may be referred to a “preventive medicine” team within the same Family Medicine Unit. The IMSS physicians have refused to screen patients for diabetes, which has created a significant loss-to-follow-up problem [41]. The physicians reportedly believe that screening is not a good use of their time (wanting lower level professionals to perform the test); however, requiring the patient to make another appointment to be screened frequently results in the patients not coming back at all because of lack of time. This could easily be solved if the patient could be immediately screened by a nurse or other technician.

Once diagnosed, the patient will be seen by the physician for treatment. The “preventive medicine” team includes a nutritionist, a social worker, a nurse, and sometimes another type of health educator. These teams provide some one-on-one health counseling and offer classes on nutrition/exercise. However, they do not manage patient care in coordination with the referring primary care doctor. If the patient requires a referral to a secondary level physician/facility, the referral contains limited information on the patient’s situation. Although the patient’s medical record is electronic, there is no interconnectivity between the medical records kept at the various levels and hence no comprehensive portable record.

If a patient presents at a Family Medicine Unit with a DIABETIMSS team, the team will work together in a coordinated way to care for the patient. This includes visits with the nurse, social worker, nutritionist, and dentist. The plan for DIABETIMSS asks that the immediate health team, comprised of the nurse, family physician and social worker, meet briefly at the start of each day to discuss the dynamics and cases for the day. The nutritionist and dentist are brought into these meetings only as necessary [46].

Wait times for patients to receive care beyond the primary level are reported to be a problem in both systems. Patients frequently wait 2-3 months for a referral to a higher level, which often leads to a loss-to-follow-up [40, 41]. Similarly, patients also have to make multiple visits for blood draws and follow-up consultations on lab results which also extends the course of
diagnosis and initiation of treatment. This is not dissimilar from the course of events in other countries, but it is a barrier to care.

Although SSA has recently completed a revision of the clinical guidelines for the diagnosis and treatment and control of type 2 diabetes for all providers in the public health system, there is recognition by the Secretariat of Health that these norms may not be optimally followed due to poor dissemination. The Diabetes Specific Program of Action proposes that efforts be undertaken to improve the relationship among all institutions of the health system to better distribute the clinical guidelines [42]. IMSS, as previously mentioned, has its own clinical guidelines for diabetes care that were last updated in 2006. However, they were not well disseminated and therefore not followed.

There is no national estimate of the percentage of persons living with diabetes who following recommended treatment/therapy. Such a number is very difficult to obtain, even in more developed countries. Part of the problem in obtaining such a figure is that the number of people living with diabetes is underestimated. In the United States nearly a quarter of the population believed to be living with diabetes is not diagnosed [48]. The 2000 National Health Survey (ENSA) in Mexico found that only 77% of those found to be living with diabetes had a previous diagnosis [9]. Consequently, if an estimate of 25% were applied to Mexico, nearly 1.5 million Mexicans would be living with the disease without knowing it. However, while the US has been able to publish statistics about the number of adults with diabetes by diabetes medication status, Mexico has not been able to compile similar statistics. A recent study, however, has demonstrated, that Seguro Popular has improved blood glucose among poor adults with diabetes in Mexico, compared to those with no insurance [49]. The study demonstrated that enrollees in Seguro Popular adhered better to therapy, as demonstrated by greater use of insulin, more glucose testing, and more frequent physician visits.

Medical Products/Resources

The Official Mexican Norm (NOM015-SSA2-1994) for the Prevention, Treatment and Control of Diabetes Mellitus at the Primary Care Level defines the treatment protocol for type 2 diabetes (excluding gestational diabetes). It was last updated in 1994 and does not reflect the advancements in pharmacological treatment or self-care. It is incongruent with the current treatment guidelines, although officials report that a new Norm will be published in 2010 that will align the two documents [46]. The Universal Catalogue of Health Services (CAUSES) 2008 publishes the drugs and treatments covered by Seguro Popular. It lists metformin, glibenclamide, intermediate insulin in NPH injectable solution, rapid action human injectable solution, prevastatin, glargine insulin, and other medications as indicated by specialists and cites the Norm. However, the Clinical Guidelines list other drugs not found in CAUSES. Some of these are purchased in small amounts by the UNEMES, but if they run out then it is up to the patient to purchase them independently at his/her own cost. Diagnostic tests covered include fasting blood glucose testing, postprandial blood glucose testing, glucose tolerance test, HbA1c, urine microalbumin, general urine testing, lipid panel, blood chemistry testing, and urine keytone testing [34]. Blood glucose meters and strips, along with diabetic shoes and prosthesis are not included.
The formulary of diabetes medications covered by Seguro Popular includes: metformin, glibenclamide, intermediate insulin in NPH injectable solution, rapid action human injectable solution, prevastatin, glargine insulin, and other medications as indicated by specialists). IMSS formulary includes all of the aforementioned but extends coverage for Rosiglitazone, Pioglitazone and the analog recombinant insulins of lispro insulin and lispro protamin. ([http://www.imss.gob.mx/CUADROSBASICOS/medicamentos/](http://www.imss.gob.mx/CUADROSBASICOS/medicamentos/)).

As previously mentioned, it is not uncommon for shortages to occur for medications prescribed at the secondary level. Basic drugs such as metformin and the like are rarely unavailable because they are very inexpensive and purchased in significant quantity. One expert opined that access to insulin in both systems is a problem (although slightly better in IMSS) because there is a belief that it should only be used at the tertiary level [41]. While the practice of early insulinization is debated among experts, many believe that putting a type 2 patient with a history of uncontrolled diabetes on insulin early will reduce overall complications later by reducing the risk of extreme high/low glucose levels.

The availability of pharmaceuticals within the Mexican health system has been of significant concern over recent years. There have been numerous anecdotes of both the IMSS and the State Health Services not affiliated with Seguro Popular running out of medications, particularly near the end of the year when budgets run low and purchasing ability to replenish supplies is diminished [40, 41, 45, 50]. However, the data presented in the National Health Program 2007-2010 suggest that while the State Health Services not affiliated with Seguro Popular were only able to fill about 60% of all prescriptions, IMMS was able to fill about 90% of them. State Health Services affiliated with Seguro Popular were able to fill about 80% of the prescriptions. There was significant variation among the states in terms of performance, however, with the states of Baja California, Campeche, Chihuahua, Tabasco, Tamaulipas, and Tlaxcala filling more than 90% of all prescriptions in all of their units [44]. In general, ambulatory settings were able to fill prescriptions more reliably than hospitals.

**Self-management Support**

The ENSANUT 2005 Survey demonstrated that of those diagnosed with diabetes, only 19.6% had it well controlled, as evidenced by HbA1c levels below 8% [9, 42]. Another 40% had levels ranging between 8 and 12%, while the remainder (40.4%) registered levels above 12%. Control did vary by institution, with nearly 25% of persons in Seguro Popular keeping their diabetes under control, while in IMSS and other institutions the average was 18.5% or below. Needless to say, people with poorly controlled diabetes are at greater risk to suffer from dangerous and costly diabetes-related complications, such as diabetic neuropathy, lower extremity amputations, blindness, renal failure, increased risk arteriosclerosis leading to heart attacks and stroke, all of which lead to increased rate premature disability and of preventable hospitalizations.

As previously mentioned, the Secretariat of Health established a program for Mutual Support Groups (Grupos de Ayuda Mutua or GAM) during the previous programming period of 2000-2006. By the end of 2006, over 11,000 GAM were formed nationwide, with more than 308,000 participants [42]. No definitive case-control studies have been conducted to demonstrate if participants have better health outcomes than those who do not participate in the GAMs.
Anecdotal evidence suggests that impact of the GAMs varies significantly by site [45]. The GAMs do not engage the family members or other support networks.

As previously mentioned, patient-friendly materials about diabetes prevention and care do not appear on the website of the Secretariat of Health. However, the Secretariat does maintain the “all about health” websites (including an “all about diabetes” site) as well as provides a link to the Mexican Society for Nutrition and Endocrinology, which does provide patient information on self-care, sugar substitutes, blood glucose monitoring, and diabetes-related surgery [51]. Needless to say, however, a patient with a limited education may not recognize that endocrinology is related to diabetes and consequently follow the link. Patient education materials on diabetes are also available in hard copy at the UNEMES, but it is not clear whether they are widely available at primary care clinics.

As previously mentioned, the IMSS website does provide limited information on diabetes prevention and care. However, nothing patient-oriented related to the DIABETIMSS program is available online. Patient education materials in hard copy are available at the Family Medicine Units as a result of the DIABETIMSS programs.

Strengthening health literacy in diabetes was cited as a critical component of the Specific Program of Action in Diabetes. Specific actions, aside from the creation of the GAM, to enhance patient literacy had not been present in the previous health plan. However, the 2007-2012 Program speaks to the need to create a culture of self-care, supported by families and communities, through community workshops and school-based programs including parents and teachers addressing nutrition (particularly use of fresh, healthy foods) and physical activity. The plan also addresses partnering permanently with the Mexican Diabetes Federation’s program “United by Diabetes.” These programs would not be exclusive to users of Seguro Popular, but no evidence could be found that demonstrates IMSS support or direct involvement in these initiatives. Through the DIABETIMSS program patients receive nutritional and exercise counseling, as well as psychosocial support. IMSS also utilizes support groups as part of the psychosocial support effort, however, they are not structured in the same way as the GAM.

**Workforce**

Mexico has overproduced physicians and under-produced nurses for nearly a century, resulting in a very physician-centric approach to health care, as is common in much of Latin America. As of 2005, Mexico estimated having nearly 200,000 physicians nationwide or 20 per 10,000 population [44]. Estimates on the number of nurses nationwide have greater variation. See Table 6. The WHO reports an estimated 90,000 nurses nationwide, while the Secretary of Health counts 234,372 nurses. It is unclear whether this discrepancy is due to definition by level of training or other reasons [52]. The number of community health workers is unknown. However, there are few endocrinologists nationwide; in 2004, it was estimated that there were only 800. The National Mexican Association of Diabetes Educators is a few hundred members strong, and its members are mostly nurses or nutritionists.

There are few training opportunities for providers of diabetes care in Mexico. A few private organizations offer a “diabetology diploma” as well as a “diploma in diabetes education.” It is
unclear how many individuals such organizations have trained. There are three main non-governmental organizations related to diabetes in Mexico: Mexican Society of Nutrition and Endocrinology, Mexican Federation of Diabetes, National Mexican Association of Diabetes Educators. Many of these offer training or publicize training opportunities. For example, the Mexican Diabetes Federation posts training opportunities on its website. However, many of these listings are for international congresses or topics related to diabetes, such as obesity. The Mexican Society for Nutrition and Endocrinology also posts many such events. Neither offers any specific training of its own design. The pharmaceutical industry sponsors some training around diabetes for physicians in Mexico, although many question whether the training is scientifically sound or whether it is more focused on selling product.

Table 6: Estimated Number of Physicians and Nurses in Mexico by Employer

<table>
<thead>
<tr>
<th>Personnel</th>
<th>Social Security (IMMS, ISSSTE, etc)</th>
<th>Other Public Sector</th>
<th>Private Sector</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physicians</td>
<td>74,968</td>
<td>67,485</td>
<td>55,173</td>
<td>197,626</td>
</tr>
<tr>
<td>Nurses</td>
<td>109,234</td>
<td>87,441</td>
<td>37,697</td>
<td>234,372</td>
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</table>

Source: Secretariat of Health, National Health Program 2007-2012

Physicians in Mexico are required to complete credits in continuing medical education. IMSS has a division dedicated to training of its medical staff, but most of the offerings are focused exclusively on physicians. Over 2006-2007, a continuing education program on diabetes care was offered to IMSS physicians. As previously mentioned, health professionals (physicians, nurses, social workers, nutritionists and dentists) within the 429 Family Medicine Units of IMSS were provided 10 days (80 hours) of in-person training in diabetes and in reorientation of care as part of the DIABETIMSS program. For those unable to attend the training in person, a 200 hour internet-based distance learning program was offered.

As previously mentioned, the Diabetes Mellitus Specific Program of Action for 2007-2012, speaks to the need for development of competencies and skills of health professionals that participate in the treatment of people with diabetes and their families. Specifically, it mentions that diplomas in the clinical prevention of diabetes and other chronic illnesses would be developed, along with workshops on early insulinization, appropriate nutrition, and food labeling. The plan also addresses the need to draft and distribute materials for health professionals to help prevent, diagnose, and control diabetes complications, including early detection and treatment of diabetic retinopathy, diabetic foot, cardiovascular and cerebrovascular risk factors, and diabetic nephropathy. Lastly, it includes the evaluation of care protocols and clinical guidelines for their distribution and use at the Specialty Medical Units for Chronic Disease.

Health Information Technology

Mexico has a highly developed and well-functioning health information system that has made significant progress in recent years. Article 7 of the General Health Law, passed in 2004, states that the Secretariat of Health is charged with promoting the establishment of a national health information system and that the system should focus on birth, death, illness and injury statistics; demographic, economic, social, and environmental health factors; and available material, human
and financial resources for protecting the health of the population and for use by the population [53]. Mexico had a strong tradition of epidemiological surveillance prior to the General Health Law, evidenced by a decades of national health and nutrition surveys, mortality registry, disease registry, etc. However, it should be noted that Mexico, like many other countries does not maintain a disease registry for chronic diseases, including diabetes; typically only “communicable diseases” are considered “notifiable.” Subsequently diabetes data is generally collected from surveys and mortality registries.

The General Directorate of Health Information (Dirección General de Información en Salud, DGIS) within the Secretariat of Health is charged with all health information coordination across the sector. However, gathering general disease data from across the various health organizations in the country remained and remains a challenge. These data are procedure-based, as opposed to disease based, and are submitted by all the various public health establishments. Coordination and standardization in collection of information posed a problem, as so many different variables were collected at the various levels of operation (jurisdictional, delegational, state, federal) by each of the institutions. Data from the private sector remains excluded from these processes to date [54].

To this end, as early as 1981 efforts were made to work collaboratively to improve communication around health information. The Inter-institutional Group on Health Information (Grupo Interinstitucional de Información en Salud, GISS) was formed in 1983 to serve as a link between health sector authorities to work together on training integration, production, processing, systematization, and dissemination of information. However, it seems that little real progress was made until nearly 2000, when greater emphasis was placed on streamlining data. The number of variables collected was condensed by more than 2000, data collection was shifted from quarterly to monthly, data on mental health and HIV/AIDS were added, intermediate formats for data collection were reduced and electronic transmission of data to the DGIS was made possible. However, harmonization of common indicators across the sector is still a long term goal, as well as obtaining data in real time that would advance health planning and evaluation.

A separate “Specific Program of Action 2007-2012: National Health Information System” was developed and includes plans to continue to harmonize indicators and data collection and processing among the institutions through a new system CLUES (Clave Unica de Establecimientos de Salud; Unique Key for Health Establishments). It also mentions beginning to disaggregate morbidity and mortality data by sex, a significant weakness in the current system, as well as exploring the development of and guidelines for electronic medical records [54]. This Program does mention diabetes, but does not go into great detail about any specific disease or condition. However, the Specific Program of Action for Diabetes discusses the development of a module for chronic diseases, including diabetes, within the Unique Platform of the National System of Epidemiological Surveillance. It does not appear that this Platform is or will be linked to the CLUES system. The plan also indicates that a National System of Indicators in Diabetes will be established and operated. The indicators are listed in Annex 3 of the Mexican document and take into account socio-ecological constructs recognized nationally and internationally [42].
Health information at the level of the individual has improved as a result of recent reform efforts. The development of the National Health Cards was a key first step in systematic, standardized patient information collection across Mexico. While portable, the patients must remember to bring the cards for the data to be utilized by various health providers, a clear weakness, but an improvement in continuity of care in the absence of electronic medical records.

**Health System Response to HIV**

*Financing and Expenditures*

In the 2008 Report on the Global AIDS Epidemic, Mexico reported to UNAIDS that it spent more than $176 million dollars on HIV/AIDS as of 2005 [55]. Using the same methodology, the Government of Mexico calculated expenditures for 2006 and 2007. See Table 7. During this time, investment in HIV/AIDS care grew dramatically, and the cost nearly doubled. The increase in expenditures is largely attributable to anti-retroviral medications (ARVs). It should be noted, however, that the number of people on treatment only grew from 30,624 in 2005 to 46,018 in 2007 [22, 55]. In 2005, roughly 99% of this amount came from domestic sources, with only 0.1% from bilateral assistance and 0.7% from other international sources, and this did not change significantly over the next two years.

**Table 7: Expenditures for HIV/AIDS in Mexico, 2005 and 2007**

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<thead>
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<th></th>
<th>2005 Expenditure (Million US Dollars)</th>
<th>2007 Expenditure (Million US Dollars)</th>
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<tbody>
<tr>
<td>Total for Prevention (including some components not listed below)</td>
<td>$40.663</td>
<td>$66.076</td>
</tr>
<tr>
<td>Communication for social &amp; behavioral change</td>
<td>$0.291</td>
<td>$2.878</td>
</tr>
<tr>
<td>Voluntary counseling and testing</td>
<td>$2.950</td>
<td>$3.077</td>
</tr>
<tr>
<td>Programs for sex workers &amp; clients; for MSM; harm reduction for IDUs</td>
<td>$5.227</td>
<td>$8.380</td>
</tr>
<tr>
<td>Condom social marketing, public &amp; commercial sector condom provision, and female condom</td>
<td>$3.369</td>
<td>$6.429</td>
</tr>
<tr>
<td>Prevention of mother-to child transmission</td>
<td>$4.472</td>
<td>$6.510</td>
</tr>
<tr>
<td>Total for Care and Treatment</td>
<td>$122.333</td>
<td>$259.783</td>
</tr>
<tr>
<td>Antiretroviral therapy</td>
<td>$103.396</td>
<td>$213.247</td>
</tr>
<tr>
<td>Orphans and Vulnerable Children</td>
<td>$0.036</td>
<td>0</td>
</tr>
<tr>
<td>Total for Program Support</td>
<td>$12.404</td>
<td>$13.372</td>
</tr>
<tr>
<td><strong>Total reported domestic public and international expenditure (excludes private sector)</strong></td>
<td><strong>$176.052</strong></td>
<td><strong>$339.791</strong></td>
</tr>
</tbody>
</table>


The single greatest element contributing to HIV-related expenditures in Mexico is the cost of ARVs. Until February 2008, each of Mexico’s public health systems separately negotiated the price of ARVs with the pharmaceutical industry, resulting in vastly different expenditures for HIV treatment across Mexico. As late as May 2008, the cost per patient per year on ARVs varied as much as $2,800 US dollars [50]. However, the Presidential Decree of February 2008
required all health systems to collectively negotiate the prices of ARVs found on the national
drug formulary, resulting in savings. All ARV prices are now listed publicly on the website of
the National Center for the Prevention and Control of HIV/AIDS (CENSIDA) to reduce risk of
corruption around pricing.

The majority of people on treatment in Mexico receive their care through the Secretary of
Health. By the end of 2008, 27,013 patients were on treatment through Seguro Popular/SSA,
and 20,696 people were on treatment through IMSS [22]. HIV/AIDS is considered a condition
leading to catastrophic expenditures under the Seguro Popular System in Mexico. However,
treatment for HIV/AIDS under the Catastrophic Fund is limited to ambulatory antiretroviral
treatment and prematurity in the case of mother to child transmission. Effectively this means
that other HIV/AIDS related expenditures must be paid for from sources other than the
Catastrophic Fund. Seguro Popular covers 25 other exams, preventive measures, treatments, and
surgeries related to HIV/AIDS [56]. This means that patients may face some out of pocket costs
for therapies or exams not covered under Seguro Popular, including some inpatient costs, if
hospitalized. In 2009, however, testing for CD4 and viral load were added to the list of services
provided under the Catastrophic Fund[22]. However, if a patient seeks care at a CAPASITS or
an SAI, a specialty AIDS and STI center within an SSA Hospital, there is no cost to the patient
for any care provided there [40]. Care even extends to supplying medications for opportunistic
infections and dental care. CAPASITS and SAIs will be discussed in greater detail under the
Service Delivery section.

Patients have also historically had to pay out of pocket costs for ARVs when the public
pharmacies faced stockouts. However, over the past two years, more careful monitoring of drug
supplies has been undertaken in both systems. CENSIDA has created a reporting system for
stockouts to help ensure that no patient is denied access to his/her ARVs because of supply chain
issues (forecasting, purchasing, stocking, transporting, monitoring supply, etc). No similar
system exists for IMSS, but many patient advocacy groups work with patients and IMSS sites to
provide medications in the case of shortages.

Within IMSS, the cost of care for a person living with HIV/AIDS is part of the regular IMSS
budget. There is no special-carve out or fund within the IMSS system for HIV/AIDS. The law
dictates that ARVs must be provided free of cost to patients within the IMSS system, however,
there may be out of pocket costs related to other medications or exams, including CD4 and viral
load tests.

Policy

As part of the National Health Program 2007-2012, the Secretariat of Health published the
Specific Program of Action in Response to HIV/AIDS and STIs. Like the other specific
programs of action developed within SSA, it includes specific objectives, strategies, lines of
action, and indicators. The overarching objective is “to diminish the growth and the effect of the
HIV/AIDS epidemic and other STIs in the country through strengthening the response and
accumulated experiences of all sectors that will permit all persons, particularly key populations,
access to prevention services and care to increase their ability to improve their self-
management/care in sexual health” [57]. The specific strategies to be undertaken as part of the Program are found in Table 8.

Table 8: Strategies within the Specific Program of Action in Response to HIV/AIDS and STIs

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Prevent the transmission of HIV and control the AIDS epidemic</td>
</tr>
<tr>
<td>2.</td>
<td>Prevent and control STIs</td>
</tr>
<tr>
<td>3.</td>
<td>Provide comprehensive, quality health services to persons with HIV</td>
</tr>
<tr>
<td>4.</td>
<td>Strengthen activities to promote sexual health</td>
</tr>
<tr>
<td>5.</td>
<td>Bolster policies to reduce stigma, discrimination, human rights violations and homophobia in key populations.</td>
</tr>
<tr>
<td>6.</td>
<td>Strengthen the intra- and inter-sectoral coordination to the national response in the area of HIV/AIDS and STIs.</td>
</tr>
</tbody>
</table>

The Secretariat of Health, through CENSIDA has published numerous prevention and treatment protocols for HIV/AIDS. All are widely available and downloadable through the CENSIDA website, and appear to be updated fairly regularly, with the latest edition of the ARV treatment guidelines being published in 2008. SSA sends hard copies of the guidelines to the various SSA health facilities, as well as to the headquarters of other public health systems within Mexico, including IMSS. Despite the fact that the guidelines issued by SSA are approved by the Consejo de Salubridad General (National Council on Health), giving them force of law, IMSS had been developing its own set of treatment guidelines in the hopes that IMSS physicians would be more likely to use them. Further discussion about actual usage will be provided in the section on service delivery. No incentive mechanisms are in place to promote the use of the guidelines in either system.

As HIV/AIDS is an infectious disease, as well as a chronic disease, it is mandatory that all cases be reported. Each health system maintains its own disease registry, but all the surveillance data (disease registry and mortality) are ultimately submitted to the General Directorate of Epidemiology of SSA and CENSIDA as part of the national surveillance program for HIV/AIDS. In addition, within SSA, an actual database of treatment history for all patients is maintained. IMSS is far more decentralized with such data being maintained at the Delegation level, if at all. Trouble sometimes arises with this notification system as patients move between systems. While this is technically not allowed, some patients attempt to seek care in more than one system due to perception of quality of care, availability of medication, migration, fear of stigma/discrimination, etc. Experts in the systems do not believe this has resulted in an exaggerated number of notified cases. Rather, many experts believe that the number of notified cases is an underestimate of the HIV positive population in Mexico.

Prevention efforts have been greatly emphasized in Mexico’s HIV/AIDS response. The prevention response has been aligned to the data around the modes of transmission, with the greatest emphasis being placed on sexual transmission. A full strategy around prevention was elaborated and defines the roles for both public and private players. CENSIDA has funded numerous civil society prevention projects throughout the country, with the greatest concentration being found in Mexico City [22]. The plan places emphasis on strengthening the civil society response to the epidemic, which has been a strong role in advocating for the rights of people living with HIV/AIDS. Another area of emphasis was on mass media campaigns.
During 2009, CENSIDA focused on two campaigns in particular: 1) the vulnerability of women facing HIV/AIDS and 2) the stigma, discrimination, and the homophobia associated with HIV/AIDS get in the way of prevention and care (ibid). A key piece of the latter campaign was Mexico’s decision to participate in “World Day in the Fight Against Homophobia,” celebrated there starting in 2007.

In comparison, little can be found about prevention efforts within IMSS. No specific program about prevention or awareness can be found on their website, although some limited information about the basics of the disease can be found only with a “key word search.”

Counseling and testing is a component of prevention as well. Rapid testing is not yet the norm across Mexico, but CENSIDA has been working to standardize it in SSA clinics. All pregnant women in Mexico are supposed to be offered free HIV/AIDS counseling and testing. Opt-in testing like this is a critical step to helping reach women at risk for contracting HIV/AIDS, however, an opt-out approach may help further prevention efforts to combat stigma and discrimination by normalizing the screening for everyone.

Finally, Mexico was awarded a grant from the Global Fund to Fight AIDS, Tuberculosis and Malaria during round 9 in July 2009 for $31 million for work between 2010 and 2014. The proposal describes that it was developed “in response to the gaps and limitations documented in the National Action Plan 2007-2012” [58]. The initial request was for nearly $76.5 million, and although that amount was not authorized, it is notable that this is the first time in the history of the Global Fund that Mexico is receiving an award and that the award is for prevention. The application notes:

The goals of this proposal and the federal government’s long-term health strategy are consistent with each other. The program will be implemented in the 44 cities where the burden of HIV among MSM and IDU is highest. Services will be offered at community meeting places and at health centers through joint government and civil society efforts. The project will begin with a situational assessment among the key populations that will be used to develop educational materials and to adapt interventions to the specific needs of key population subgroups (considering identity, gender, practices, social/cultural context, etc.). Concurrently, there will be intensive training activities to increase technical and managerial capacity of service providers, as well as scaling-up of programs to decrease stigma and discrimination towards key populations. The program is designed to be both sustainable and expandable to other cities once this Global Fund project finishes. (Global Fund to Fight AIDS, Tuberculosis and Malaria website)

**Service Delivery**

As previously mentioned the treatment guidelines issued by SSA are approved by the Consejo de Salubridad General (National Council on Health), which gives them the force of law. However, there is significant variation on how well the guidelines are followed across the various systems. Within SSA, obligatory trainings on the treatment guidelines for physicians seeing PLWHA are conducted 2-3 times a year. Until recently, there was no monitoring system in place to ensure that physicians are complying with the guidelines within IMSS. However, the new information system known as SALVAR (Sistema de Administración y Vigilancia de ARV or ARV
Administration and Surveillance System) provides CENSIDA with a tool to ensure that physicians are following the clinical management guidelines [57]. SALVAR will be discussed in further detail in the Information System section. There is a perception among patients that physicians (who are more frequently infectious disease physicians) within SSA are better equipped to provide care and treatment than physicians in other systems because they have this training [50].

Within IMSS the treatment guidelines are not well-utilized, and SALVAR or a similar information system is not in place. One study found that two possible reasons for this exist: 1) the guidelines were published by SSA and not IMSS and there is strong institutional rivalry; and 2) many physicians within IMSS receive their information about HIV treatment regimens from the pharmaceutical industry who are interested in selling their particular products [50]. The latter may be less of an issue now than in previous years given that price negotiations are now handled at a centralized national level, although specific purchasing is left up to IMSS Delegations to conduct, which means there can be variation in quantities ordered, regardless of guidelines.

The National Health Program 1997-2001 called for the first “Model for Medical Care for patients with HIV/AIDS,” that became known as “Specialized Services for AIDS Care” (Servicios Especializados para la atención del SIDA or SEAs) [22]. The SEAs were intended to consist of a multidisciplinary medical team at the ambulatory care level that would be integrated within existing hospitals within each State and the Federal District. The 2002-2007 Program, took this initiative a step further to extend care. As previously mentioned, specialty health units for various diseases and conditions were established within the Secretariat of Health starting in 2003. Ambulatory centers for the Attention and Prevention of AIDS and STIs (CAPASITS) were established as part of this initiative to improve access to comprehensive health services, including ART as well as prevention and diagnosis of HIV and STIs.

The SEAs were renamed Integrated Care for Persons with HIV/AIDS (Servicios de Atención Integral para Personas con VIH/SIDA or SAI) and grew from 27 in 2000 to 108 in 2006 to increase access to care where CAPASITS were not found [57]. As of 2009, 56 CAPASITS exist across Mexico and employ a comprehensive team of health professionals including physicians, nurses, social workers, psychologists, dentists, lab technicians, and secretarial staff. A directory of all the CAPASITS, including the managing physician, hours, and location are available through the CENSIDA website. They are usually free-standing, newly constructed small clinics that have a few exam rooms, a dental exam office, a lab, offices for the staff, and a large group meeting room for workshops and trainings.

Within the CAPASITS, care is highly coordinated for the patients, evidence by comprehensive patient management by the various providers, follow-up, and record keeping. Waiting times for patients is reportedly not a problem. SAI is reported to function in a similar manner, with highly integrated teams. However, a disconnect remains if a patient requires hospitalization or non-ambulatory care outside of the CAPASITS, with the exception of a few very specialized hospitals within major metropolitan areas such as Mexico City. Medical histories and patient files are not readily transferable between establishments, and coordination between levels depends on physician relationships or patient self-advocacy. In fact, this weakness has been
pointed out within the Specific Program of Action 2007-2012 in response to HIV/AIDS as an area for work.

Within IMSS, the coordinated team approach to HIV/AIDS care found in the CAPASITS and even within DIABETIMSS sites is not well-established. PLWHA who receive their care within IMSS are mixed in with all other patients and the IMSS bureaucracy. This frequently translates into long wait times for appointments (medical as well as psycho-social), prescription refills, laboratory tests, and the like. This also means a general lack of coordination among the various pieces of the health system that touch the life of the PLWHA. If the person does not have the time, ability, or knowledge to maneuver in the system, he or she may be lost to follow-up. A loss-to-follow-up can have devastating consequences for a PLWHA, resulting in complications, unnecessary or premature shifting to other ARVs that lead to drug resistance, or going off therapy. Sometimes this means that the individual will attempt to seek care in more than one institution, such as through SSA, potentially causing more confusion around care.

Measuring the number of persons on ARV treatment in Mexico is a far easier task than measuring those receiving treatment for diabetes due to the sheer number of patients, the required reporting, and other monitoring systems in place. As previously mentioned, by the end of 2008, 27,013 patients were on treatment through Seguro Popular/SSA, and 20,696 people were on treatment through IMSS, and a total of 52,001 people were on estimated to be on treatment through the entire public health system [22]. Not everyone who is diagnosed with HIV needs to initiate treatment immediately. However, similar to diabetes, many people living with HIV are undiagnosed. Therefore, the number of people actually on treatment is less than the number who should be on ARV treatment. Figure 7 provides CENSIDA’s estimate of the number of people who know their status and are on treatment compared to those whose sero-status is unknown.

Figure 7:

![Estimation of persons living with HIV in Mexico in Relation to Treatment Status](image)

Source: CENSIDA, 2009
Medical Products/Resources

The “Anti-retroviral Management Guide in Persons with HIV/AIDS” defines that national treatment protocol for Mexico [59]. It provides the national formulary for approved drugs for treatment for all public health systems within Mexico, along with the prices per unit. Prior to the Presidential decree in 2008 calling for all branches of the public health system in Mexico to jointly negotiate the prices of ARVs and arrive at standardized prices, the national formulary was not universally recognized in actuality. There was significant variation between IMSS and SSA, and even more variation between the IMSS delegations, which each purchased their own drugs without any significant oversight. There were also reports of stockouts and shortages of medications across both health systems, although the problems were more common in IMSS [50]. As a result, patients would sometimes switch health care systems, if that was an option, or try to find medications in the private sector, resulting in out of pocket costs. Because of the value of the medications, there were also reports of health professionals stealing them and selling them illegally at a profit in the black market.

A critical component to HIV/AIDS care is regular monitoring of CD4 levels or viral load. Mexico has a long history of a strong laboratory network to provide this sort of testing for the patient population. Nonetheless, reports of shortages and availability of laboratory tests to monitor patients have been reported in previous years [60]. The CAPASITS and other health centers are not equipped with CD4 and viral load testing machinery; only the 9 federal laboratories maintain this equipment and serve all 32 federal entities [46]. CENSIDA reports that results are returned to the providers within 7 days of testing. It should be noted that delays in obtaining and reporting the results of such tests not only challenges the ability to manage treatment outcomes, but they also increase the risk of patients failing to adhere to their therapies.

IMSS has its own network of laboratories where CD4 and viral load testing are conducted. The machinery to undertake these tests usually only exists at the State or Delegación level. While this may be the most cost-effective given the number of persons requiring this testing, it frequently means delays in reporting the results to the managing physicians and patients. These delays could impact quality of care if there are communication problems between the patient and provider.

Unlike diabetes care, there are no tools or at-home diagnostic/monitoring devices that need to be utilized daily by a patient with HIV/AIDS. However many persons living with HIV/AIDS are now living longer, healthier lives and are suffering from other chronic comorbidities such as diabetes. Even if the individual is living with HIV/AIDS, monitoring tools like glucose meters/strip or blood pressure monitoring devices are not provided free of cost.

Rapid tests for HIV diagnosis are not yet universally used across Mexico. They are used universally in CAPACITS and in ambulatory settings providing care to pregnant women who have tested positive for syphilis and to persons with tuberculosis. However, rapid tests are not always available in the primary care settings of IMSS or in public health clinics of the Secretary of health.
In 2007, over US $11 million was spent on condoms by the Government of Mexico to combat HIV/AIDS [61]. The majority of this was for direct provision of male condoms, and smaller portions to social marketing programs and for the purchase of female condoms. However, it is interesting to note that nearly three times as much was spent on activities to ensure safe blood. A total of 140,597,312 condoms were distributed by all public government agencies involved in health, including 95,549,577 by the Secretariat of Health and 42,957,757 by IMSS [62]. The number of condoms distributed has on average increased by 20,000,000 each year since 2002.

**Self Management Support**

Todoensalud.org, the website developed to provide health information for patients, does not have any information about HIV/AIDS. However, CENSIDA has produced significant amount of printed and online materials available for the public. On-line resources include basic information on HIV testing, using condoms (both male and female), rapid testing, forms of transmission, methods for prevention, sexually transmitted diseases, and human rights (including sexual rights, sexual diversity, and stigma/discrimination/homophobia). These materials are user-friendly, although they are not found immediately on the homepage of CENSIDA and do require some minor searching (http://www.censida.salud.gob.mx/interior/prevencion.html). Hard copy materials and informational posters are found within the CAPASITS and SAIs for patients coming in for testing or treatment.

Similar materials are scarce within IMSS. No specific place on their website could be found as a dedicated resource on the topic of HIV/AIDS. The main page for health information (http://www.imss.gob.mx/salud) does not address HIV directly. Such information is buried under the STI section of the women’s health page. The PREVENIMSS pages are no better: while they are divided into sections based on age and gender, none effectively speaks to HIV prevention, screening, treatment or care.

Psychosocial support is a key component of the care offered in the CAPASITS. Counseling is a standard part of HIV testing, both pre-and post-test. All persons who test positive for HIV and seek care at the CAPASITS are required to participate in one workshop at a minimum. Patients who are initiated on treatment are required to come in every 2 months for their medications and receive CD4 testing and viral load testing 4 times a year. If they appear to be non-compliant with treatment regimens, they are required to attend additional training. They are also offered additional visits with the psychologist or social worker, as needed. CAPASITS do not formally refer patients to NGOs or other support groups, although they often have community contacts and can facilitate communication with such organizations.

Within IMSS, pre-and post-test counseling is the standard of care. However, there is no evidence that persons testing positive then receive additional education/training. There may be additional referrals to a psychologist or a social worker elsewhere in the IMSS system, depending on the case. IMSS does not formally refer patients to NGOs or other support groups.

Neither system appears to offer any programs or support services to family members of people living with HIV, although linkages to NGOs that do offer these services exist. This kind of
education and support, if the person discloses his/her status and is encouraged to involve a loved one, has the potential to improve adherence to treatment and overall outcomes, as well as spread prevention messages.

**Workforce**

In Mexico, most care for people living with HIV is provided by internal medicine physicians due to low numbers of infectious disease physicians. No national data are collected on the total number of infectious disease physicians in Mexico. However, one possible proxy is the membership in the Mexican Association of Infectology and Clinical Microbiology. The total membership is about 500 strong, with the greatest concentration of members in Mexico City (www.amimc.org.mx), which represents physicians working in both the private and public sectors.

Another challenge related to human resources for HIV care is that because relatively few physicians and health teams have received specialized training, there is little patient choice in health care provider. In large metropolitan areas, such as Mexico City, there may be some limited choice, but for the most part, patients in either system cannot choose their health care professional. They are assigned a treating physician. If that physician is not well-trained, inopportune initiation of treatment is possible, which can negatively impact the patient’s health. Similarly, if the physician is unable to effectively communicate with the patient about the importance of adherence, the patient may lapse in treatment and consequently develop drug resistance or opportunistic infections.

Training of health care providers in HIV care has been a long-standing challenge in Mexico [60]. The development and dissemination of treatment guidelines by, as well as steps to insure their implementation have helped. As previously mentioned, within SSA, obligatory trainings on the treatment guidelines for physicians seeing PLWHA are conducted 2-3 times a year. SSA also has published care guidelines for nurses, as well as guides on specific topics such as anal-rectal health and injecting drug users; all are downloadable on the CENSIDA webpage. Training around some of the psycho-social aspects of care is also available, for example a strategy was published in 2008 to sensitize personnel about homophobia and discrimination.

Unfortunately, however, no similar trainings exist within the IMSS system around HIV care. IMSS maintains an entire division called “Coordination in Health Education” (http://edumed.imss.gob.mx/edumed/index.htm) that is accessible via internet. However, no training opportunities or materials could be found related to HIV. One government official opined that the best training opportunities available to IMSS physicians were typically conferences or workshops sponsored by pharmaceutical manufacturers.

Additional learning opportunities for health professionals exist through professional conferences and workshops. Mexico was host to the International AIDS Conference in 2008, which drew a huge audience and provided ample opportunity for discussion of technical and policy issues related to HIV care and treatment.
Information Technology

Information technology around the monitoring of the HIV/AIDS epidemic and patient care in Mexico has been an ongoing challenge that the General Directorate for Epidemiology (DGE) and CENSIDA now seem to have under solid control. When a person is diagnosed with HIV, the case is notified to the DGE through the Nominal Registry of HIV Seropositives and the Nominal Registry of Cases of Congenital Syphilis. If/when that person develops AIDS, he/she is added into the National Registry of AIDS Cases. DGE manages this data, along with data from the Unique Information System of Epidemiological Surveillance and the Sentinel Surveillance Surveys to characterize and monitor the epidemic in Mexico. This information is not readily accessible to centers via a “live” interface or website. However, DGE consolidates and analyzes this information and produces regular periodic publications on the epidemic.

Separately, CENSIDA maintains a database known as SALVAR or System for the Administration, Logistics and Surveillance of Antiretroviral Medications. Developed in 2006 and launched in 2007, in coordination with the General Directorate for Information Technology, this integrated system serves as a live medical record for patients receiving ART as well as an inventory of what medications are needed where and for whom. The database also allows officials at CENSIDA to check physician prescribing patterns to ensure that treatment is in accordance with the National Treatment Guidelines. SALVAR is used in all the CAPASITS as well as in the SAEs, nationwide. According to staff at the CAPASITS, there is clear training provided to all professionals entering patient data, as well as periodic updates as improvements are made to the system.

CENSIDA also regularly synthesizes the data collected nationally through the DGE and publishes it periodically either online or in hard copy. This includes updates on number of people living with HIV, number of people on treatment, cost of medications, and other details of the nature of the epidemic.

Information gathering is not as straightforward within the IMSS system related to HIV care. Although IMSS does utilize electronic medical records, there is no centralized automated reporting system related to HIV/AIDS care. HIV and AIDS cases first are reported to the delegation level, which then reports to the national level to DGE. While reporting is supposed to happen on a regular basis, it does not, according to IMSS officials. Treatment regimens per patient are supposedly maintained at the individual IMSS health center, which then uses the information to request orders for medications to the delegation level. The delegation level, in turn, submits its consolidated request twice a year to the national office. However, this process does not allow for overall monitoring for compliance with guidelines. A patient treatment database is not maintained or consolidated with the SALVAR database.

Discussion

Mexico has implemented a model of coordinated care at the primary care level for both diabetes and HIV/AIDS through the development of UNEMES. This model is philosophically rooted in the chronic care model, which has been evaluated extensively. While the long term impact of
implementing the UNEME model on the health of persons living with these diseases is not known yet, initial signals seem to point in a positive direction. However, the cost to the system for this sort of care remains unanswered. CAPASITS appear to be highly utilized and functioning well. The UNEMEs for Chronic Diseases have not caught on in the same way and some are sitting empty. Why? The model is the same.

Perhaps the answer lies in the public’s perception of diabetes and its comorbidities versus that of HIV/AIDS. If the model of integrated care through small health teams is indeed effective, then perhaps the answer is fewer specialty clinics and more primary health clinics using this model. The patient would then have a “medical home” to address all his/her medical issues and not have to go to a specialty clinic for the management of chronic diseases that he/she faces. Streamlining the care into a single site would also theoretically improve harmonization of medical records.

However, the problem of continuity of care appears consistently across systems when the patient experiences acute episodes of disease, forcing him or her to seek care at a higher level facility. That facility almost never has access to the patient’s full medical history. If the patient cannot remember the extent of previous diagnosis, the medications and therapies he/she is on, and their pattern of test results, there is no way for the provider(s) at the secondary or tertiary care level to be aware of this. Furthermore, there is also no transfer “down” of information from the higher level care facilities to primary care when the patient’s health normalizes.

There is a cost-trade off between investment in primary health care and secondary/tertiary health care. The availability and accessibility of facilities to handle acute complications is limited in many parts of Mexico, as seen in the example of renal dialysis. The sheer volume of patients outnumbers the number of available facilities. The reason is economic. Renal dialysis is expensive. One could argue that additional investment in primary care with strong coordinated care could reduce the volume of patients needing care at the expensive tertiary level. However, that does not negate the need for services altogether.

This creates an ethical dilemma. People are dying due to lack of services they are theoretically entitled to. What is the opportunity cost of extending these services? The cost is the lost ability to expand primary care centers that could care for more people and prevent or delay such complications. Does this hold true for both HIV/AIDS and diabetes? Theoretically yes, however, the number of people living with HIV pales in comparison to the number of people living with diabetes in Mexico. So, access to tertiary care seems to be less of a problem for people living with HIV.

Another ethical question then arises: are too many resources being dedicated to HIV in Mexico, given the burden of diabetes is so much greater? In terms of expenditures, diabetes is clearly costing Mexico more money than HIV. See Table 9. However, the cost per patient is much higher for HIV/AIDS than it is for diabetes, largely due to the high cost of ARVs. The cost of HIV care in Mexico far exceeds that of many other middle income countries. Mexico has already taken some important steps to lower the cost it pays for ARVs by harmonizing its purchasing, and consequently price of treatment per patient has likely decreased since 2007. Early preliminary analysis suggests that the average annual expenditure per person receiving initial ART (i.e. not rescue therapy or other more advanced combinations) has dropped
significantly. The average cost of treatment alone (not including medical visits, labs etc) per person per year was about $5,005 in 2007 [22]. By 2009, this cost had dropped to $3,445, a savings of about $1,560 per person per year. Still, as patients live longer, new therapies will be needed as the virus develops resistance to existing drugs. These therapies will continue to drive the cost up, unless a cure is found. Improved adherence can only delay the onset of drug resistance.

A similar pattern is seen with people living with diabetes. The cost of caring for a person with diabetes during the first few years is relatively inexpensive. Diabetes does not become “drug resistant” like HIV, but complications arise if the person is not able to keep the diabetes well-managed. Such complications can drive up the cost of patient care rapidly, resulting in very high cumulative costs for management of the complications [63]. More pharmaceutical products are typically needed, more self-monitoring is needed, and acute care episodes (resulting in hospitalizations) related to nephropathy, neuropathy, retinopathy, and other macrovascular complications may occur more frequently. While the drugs themselves may not drive up the cost in the same way they do with HIV/AIDS, the other components do increase expenditures.

Table 9: Mexico 2007 Comparison of Disease Burden and Cost

<table>
<thead>
<tr>
<th></th>
<th>Diabetes Mellitus</th>
<th>HIV/AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent prevalence</td>
<td>10.6</td>
<td>0.3</td>
</tr>
<tr>
<td>People living with disease</td>
<td>6,115,700</td>
<td>200,000</td>
</tr>
<tr>
<td>People receiving ART</td>
<td>NA</td>
<td>44,616</td>
</tr>
<tr>
<td>Total estimated expenditure</td>
<td>US $3,461,699,000*</td>
<td>US $339,791,000¹</td>
</tr>
<tr>
<td>Expenditure for care and treatment</td>
<td>US $3,461,699,000*</td>
<td>US $259,783,000¹</td>
</tr>
<tr>
<td>Average annual expenditure per person for Care (expenditure for care &amp; treatment/# people on treatment)</td>
<td>US $566</td>
<td>$5823</td>
</tr>
</tbody>
</table>


*Note: Estimated diabetes expenditures are national and reflect both public and private sectors. However, 96% of Mexicans receive care in the public sector.

¹This reflects total number of people nationwide on ARVs and total national expenditure, not only those of IMSS and SSA

Why is it that so many resources have been dedicated to HIV? The answer may lie in the civil society response to both diseases. The activist community for HIV/AIDS both within Mexico and internationally has been vocal and well-organized for more than a decade. Perhaps this is because so many were witness to the ravaging effects and fear generated by the disease in the early days of the epidemic, particularly prior to the development of ART. Perhaps the communicable nature of the disease played a role in society’s perception of the needed response, vis a vis that of a non-communicable disease.

While awareness has grown around the burden of diabetes, civil society has not rallied around the disease in the way it has for HIV/AIDS. Subsequently, dollars have not flowed to prevention and treatment in the same way either, although the Government of Mexico has paid more attention to the epidemic than most countries. Broad media campaigns by both IMSS and the
Secretariat of Health are geared at reducing obesity and all of its related comorbidities, including diabetes. Diabetes is not covered under “Catastrophic Funds” by the Mexican Government. In fact, there is significant quiet political pushback on keeping chronic diseases out of such funding streams because they would quickly overwhelm and exhaust the funds.

The Mexican model of financing care for diseases that result in catastrophic expenditures is quite unique and begs the question of whether this kind of pooling of funds for the treatment of these conditions will help preserve funding for primary care. Perhaps the only problem may be with nomenclature. The Catastrophic Fund may be sustainable for rare diseases that result in catastrophic expenditures. However, diseases that are far more common (albeit potentially catastrophic), such as diabetes, can be managed through financing for primary care.

However, that approach may only work if the primary care setting is truly geared toward providing patient-centered care to best avoid and delay the onset of catastrophic complications. Mexico’s experiment with creating UNEMEs for chronic disease should not be necessary if its primary health centers were better trained and equipped to deal with chronic disease. Over the long run, this may reduce the demand for renal dialysis, but in the mean time, any cost savings could be utilized to expand dialysis services. Investment could also be shifted to focus on provider training and reorientation of care in existing primary health care settings. This may even pave the way for HIV care to be possible in such settings as well (if politically acceptable) to further streamline provision of care.
Works Cited


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Introduction to Brazil

The Federative Republic of Brazil, commonly known simply as “Brazil,” is the largest country in Latin America and is facing a significant chronic disease burden that will have an important impact on its health system. It has the greatest number of people living with diabetes in the region, nearly 6.9 million people in 2007, and one of the highest prevalence rates in the region (6.2%) [1]. Brazil has a complex health system with public and private suppliers and financiers, as well as mechanisms that implicitly link the two systems. The purpose of this work is to examine the role and response of the public sector in Brazil’s health system to diabetes and HIV/AIDS and to draw lessons and initial policy recommendations from this experience.

Basic Demographics

Brazil encompasses much of the eastern portion of South America. Its territory is divided politically and geographically into five regions, 26 states, 5,561 municipalities. It is the world’s fifth largest country by geographic area and population, with current estimates ranging from 192 to 196 million inhabitants [2, 3]. However, approximately 83% of the population is found in urban areas, with high population densities in the southeast, and the lowest in the north and center-west regions [4]. The population of Brazil is ethnically diverse, with whites comprising 53.7%, mulattos 38.5%, blacks 6.2%, others (including Japanese, Arab, and Amerindians) 0.9%, and unspecified 0.7% [5].

Economy and Development

Significant economic growth over the past few decades has raised the overall level of development in Brazil, although huge disparities persist across racial/ethnic groups, socioeconomic strata, and rural/urban areas. A military coup, alarmed by poor economic progress, interrupted democracy in Brazil in 1964. Democracy was slowly restored during the 1980s: in 1985 political parties were free to organize, in 1988 a new constitution was written, and in 1989 marked the first popularly elected government in decades. By 2007, the Gross Domestic Product was estimated to be $1,314.17 billion [3]. Industry accounts for one-third of Brazil’s GDP, making it one of the most advanced in Latin America [2]. Brazil has a strong services industry as well that includes telecommunications, shipping, banking/commerce, and computing. Brazil's economy, aided by a strong international economy until recently, grew approximately 2.8% in 2006 and 4.5% in 2007 [2]. However, significant challenges lie ahead, such as Brazil's government debt remains high, total tax burden is high, and income and land distribution remains skewed [2-4].

Brazil ranked 70th in the classification of countries in the Human Development Report 2007/2008, with an overall value of 0.8, demonstrating continual improvement over the past 33 years and an adult literacy rate is 88.6% [6]. The gross national income per capita (Atlas Method) in 2008 was $7350 [7]. However, its high Gini index score of 57 reflects the inequality in income distribution in the country [6], with the richest 10% of the population receiving 44.8% of income, while the poorest 10% only receive 0.9%. President Lula committed his government to the goals of eradicating extreme poverty, however, results are mixed and vary by region and ethnic group [4].
General Morbidity and Mortality

Brazil has been undergoing an epidemiological transition over the past few decades, with declining fertility rates, rising life expectancies, decreases in infectious disease rates, and rapidly increasing rates of chronic diseases. Total fertility rates have dropped notably over recent decades from over 6 children per woman in 1960 to below 5 in 1970, down to 3 in 1991 to 2 children per woman in 2007 [4, 8]. Although life expectancy varies by sex and ethnic group, life expectancy has risen from 67.0 years in 1991 to 71.7 years in 2004, and 72 years in 2006 [3]. White women, on average, have the longest life expectancy, followed by black women, white men, and black men. While infectious diseases (tuberculosis, diarrheal diseases, HIV/AIDS and tropical cluster diseases) still account for a large number of deaths nationwide, the leading causes of death in Brazil are now chronic in nature, including cardiovascular disease and cancers. See Table 1.

<table>
<thead>
<tr>
<th>Cause</th>
<th>Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Circulatory system diseases</td>
<td>302,682</td>
</tr>
<tr>
<td>Malignant neoplasms (cancer)</td>
<td>155,734</td>
</tr>
<tr>
<td>External causes (violence, traffic accidents, etc)</td>
<td>128,255</td>
</tr>
<tr>
<td>Respiratory system diseases</td>
<td>102,834</td>
</tr>
<tr>
<td>Symptoms, signs and abnormal clinical laboratory findings</td>
<td>85,469</td>
</tr>
<tr>
<td>Endocrine system diseases (diabetes)</td>
<td>58,867</td>
</tr>
<tr>
<td>Digestive system diseases</td>
<td>51,910</td>
</tr>
<tr>
<td>Infectious and parasitic diseases</td>
<td>46,487</td>
</tr>
<tr>
<td>Perinatal conditions</td>
<td>28,328</td>
</tr>
<tr>
<td>Diseases of the nervous system</td>
<td>19,157</td>
</tr>
<tr>
<td>Genitourinary diseases</td>
<td>17,419</td>
</tr>
</tbody>
</table>

Source: Saude Brasil 2008

Diabetes Epidemiology

By 1980, diabetes was the 7th leading cause of death [9]. Estimates from 2004 place diabetes mellitus as the fifth leading cause of death nationally according to the Brazilian National Mortality Information System (SIM) (Ibid). Reclassifications of causes of death by the WHO made it appear to drop down to 6th place, but overall mortality actually increased. By 2005, diabetes mellitus was the second most frequent cause of death among women, and the fourth among men (collapsing diseases of the circulatory system and external causes into two categories instead of listing them individually) [10]. Figure 1 demonstrates the increasing death rates due to diabetes in Brazil by geographic region. People with diabetes frequently die from related comorbidities, such as cardiovascular disease, therefore cause of death data must be examined with caution. In fact, one recent study found that cardiovascular diseases accounted for 54.5% of the underlying causes of death when diabetes was an associated cause [11].

A 1988 multi-center study to determine the prevalence of diabetes in Brazil found a rate of 7.6% (80% as Type 2, ~20% Type 1) for the adult population 30-69 [12]. The 1988 study as well as more recent mortality data demonstrated that disease prevalence varies by geographic area (See Table 2 and Figure 1), with Sao Paolo presenting the highest prevalence rates. Regardless, the
prevalence level is not necessarily incongruous with the 2007 estimate for the prevalence 6.2% among adults (20-79 years), given the different age parameters of the studies. However, some experts believe this estimate may be low, given the growing obesity burden nationwide [13]. The prevalence is expected to rise to the formidable level 11.4% by 2025 [1]. This amounts to greater than 6.9 million people living with diabetes in Brazil during 2007, the highest number in Latin America. The prevalence of impaired glucose tolerance, an indicator of people at risk for becoming diabetic, was estimated to be 7.0% in 2007, and is also expected to rise to 10.6 by 2025 (Ibid). While the Brazilian Ministry of Health is currently tracking numbers of people living with diabetes with the HIPERDIA System (to be described in section on Information Systems), they have not published more recent prevalence estimates for each state. However, overall numbers of persons with diabetes entered into the system on a state-by-state basis follow the trends in the aforementioned studies.

Figure 1: Standardized death rates for Diabetes in the population of 40 years or more by region in Brazil - 1996 the 2004.

Source: Ministry of health of Brasil, [9]

The 1988 study did not provide a breakdown of the data by racial/ethnic groups, nor did a nationwide screening program conducted in 2001. However, others have described the black population in Brazil as being at greater risk of dying from diabetes than their white counterparts [4]. The cities listed in Table 2 with the highest rates of diabetes, such as Porto Alegre, João Pessoa, Salvador, tend to be cities with large black populations.

The prevalence projections do not take into account increasing rates of overweight and obesity. It was estimated that between 2000 and 2006 an estimated 11% of adults 15 years and older were obese (8.9% for males, 13.1% for women) [14]. Overweight and obesity prevalence vary by geographical region, sex, and age, but comparison with previous surveys demonstrate both are rising across the country with the south, southwest, and center-west having the highest rates, and
women having higher rates than men [4, 12]. If these trends continue, the diabetes projections are likely to be underestimated.

**Table 2: Estimated prevalence rate of diabetes mellitus, selected cities adjusted for age, in the population 30-69 years, 1988**

<table>
<thead>
<tr>
<th>Location</th>
<th>Prevalence rate per 100</th>
</tr>
</thead>
<tbody>
<tr>
<td>BRAZIL (national)</td>
<td>7.6</td>
</tr>
<tr>
<td>Belém</td>
<td>7.16</td>
</tr>
<tr>
<td>Fortaleza</td>
<td>6.48</td>
</tr>
<tr>
<td>João Pessoa</td>
<td>7.95</td>
</tr>
<tr>
<td>Recife</td>
<td>6.42</td>
</tr>
<tr>
<td>Salvador</td>
<td>7.87</td>
</tr>
<tr>
<td>Rio de Janeiro</td>
<td>7.47</td>
</tr>
<tr>
<td>São Paulo</td>
<td>9.66</td>
</tr>
<tr>
<td>Porto Alegre</td>
<td>8.89</td>
</tr>
<tr>
<td>Brasília</td>
<td>5.22</td>
</tr>
</tbody>
</table>

Source: Ministry of Health/Estudo multicêntrico sobre a prevalência do diabete melito no Brasil

**HIV/AIDS Epidemiology**

HIV/AIDS in Brazil dates back to 1980, when the first case was diagnosed retrospectively [15]. The disease began to spread throughout the decade, largely among 20-49 year olds, largely due to sexual transmission among gay and bisexual men and unsafe blood transfusions [16]. The 1990s brought spread of the disease largely through injecting drug use, finally leading to heterosexual transmission (ibid). It is estimated that between 1984 and March 2002, the cumulative number of deaths attributable to AIDS was 105,000 [15]. Mortality began to decline among men in major areas in 1991, and among both sexes when zidovudine (AZT) was made available in 1996 (ibid). At this point, the number of new cases began to diminish overall due to significant prevention efforts (to be discussed in the HIV/AIDS policy section), with only small pockets of the population continuing to face growth in prevalence.

UNAIDS estimates that by 2001, there were approximately 660,000 people living with HIV/AIDS in Brazil, resulting in an overall prevalence of 0.6% [17]. These numbers must be viewed in the larger context of the global HIV/AIDS epidemic, given Brazil’s overall large population: by 2003, the Brazilian Ministry of Health reported 277,154 AIDS cases, which made the epidemic the 4th largest worldwide [15]. Since then, the epidemic has been viewed as largely stabilized. The estimated prevalence level remains at 0.6% (adults 15-49 years), and UNAIDS estimated that in 2007 approximately 730,000 people were living with HIV/AIDS [17]. The total number of cumulative AIDS cases notified from 1980 to 2008 is 506,499 [18].

Brazil’s epidemic is frequently described as concentrated, although it was recently characterized as “a mosaic of regional epidemics reflecting the extension and socio-geographic diversity of the country and its regional heterogeneity” [16]. The epidemic originally affected largely affluent men who have sex with men (MSM), but has expanded its reach significantly. In fact 67% of the AIDS cases reported in 2007 were men, while 33% were women [19]. Barbosa and colleagues have described incidence by category of transmission from 1980 to 2004 [20]. During the 1980s, most HIV was transmitted via male-to-male sexual transmission, but by the mid-1990s, new
AIDS cases in women had already exceeded the new cases in MSM and injecting drug users. Currently heterosexual transmission is the largest cause of exposure. See Figure 2.

**Figure 2**

Percent of total cases of AIDS by Exposure Category
Brazil, 1980-2004

<table>
<thead>
<tr>
<th>Year</th>
<th>MSM</th>
<th>Heterosexual Male</th>
<th>IDU (Male)</th>
<th>Other (male)</th>
<th>Unknown (Male)</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>1980-1988</td>
<td>54.6%</td>
<td>15.8%</td>
<td>10.0%</td>
<td>6.1%</td>
<td>3.3%</td>
<td>11.9%</td>
</tr>
<tr>
<td>1989-1992</td>
<td>33.0%</td>
<td>26.6%</td>
<td>11.9%</td>
<td>9.3%</td>
<td>10.0%</td>
<td>16.9%</td>
</tr>
<tr>
<td>1993-1996</td>
<td>33.0%</td>
<td>26.6%</td>
<td>11.9%</td>
<td>9.3%</td>
<td>10.0%</td>
<td>16.9%</td>
</tr>
<tr>
<td>1997-2000</td>
<td>22.3%</td>
<td>21.0%</td>
<td>15.7%</td>
<td>14.9%</td>
<td>14.1%</td>
<td>19.8%</td>
</tr>
<tr>
<td>2001-2004</td>
<td>34.4%</td>
<td>23.8%</td>
<td>17.6%</td>
<td>12.2%</td>
<td>11.0%</td>
<td>12.6%</td>
</tr>
<tr>
<td>Total</td>
<td>30.9%</td>
<td>22.1%</td>
<td>16.4%</td>
<td>15.6%</td>
<td>12.6%</td>
<td>12.6%</td>
</tr>
</tbody>
</table>


The Brazilian epidemic has been characterized as largely urban [15, 16]. However, evidence exists that the disease has been growing in rural areas, although the incidence rates are still fairly low [16]. The highest incidence rates have historically centered on the Southeast Region (which includes Rio de Janeiro and Sao Paulo), however, recent data suggest higher incidence rates in the Southern Region of the country (ibid).

Data for prevalence rates among specific most-at-risk populations are difficult to obtain. However, studies from 2000 demonstrated rates as high as 34.5% among some sex workers and 64% in some IDUs in urban areas [17]. New sentinel surveillance studies regarding these populations is expected to be published soon by the Ministry of Health [21].

**Brazil’s Health System**

Brazil has a well-developed national health system. It is comprised of a complex network of services encompassing both public and private suppliers and financers. Dating back to the 1970s, Brazil’s health sector was largely dominated by the private sector, comprised of a large private hospital sector and a growing private insurance sector [22, 23]. Even the Social Security System purchased services from the private sector during this time. See Figure 1. In fact, it was estimated that in 1975 almost 70% of hospital beds in Brazil were private [23]. However, in 1988, with the adoption of the new Federal Constitution, Brazil created the Unified Health
System (SUS), which was guided by the principles of “universal and equitable access to services for the promotion, protection and recovery of health, integrated in regionalized, multilevel network under the responsibility of the three levels of government (federal, state, and municipal)” [22, 24]. See Figure 2. This basically defined health care as an egalitarian right, with the state bearing the responsibility of guaranteeing it [25]. Currently, it is estimated that the SUS provides coverage to approximately 75 to 82% of the population [4, 26]. The SUS will be the focus of the current work.

Although the reforms to the health care system were written into the constitution in 1988, transition actually occurred over the course of the 1990s. Previously, system had been characterized by three subsystems: 1) a public contracting subsystem funded by compulsory salary based contributions from employers and employees and managed by the Ministry of Social Security and Social Assistance, 2) a public integrated system, financed through general taxation and managed by the MOH, and 3) a voluntary contracting subsystem, funded by some employers, employees, and the Ministry of Social Security [27].

The impetus for the reforms, as previously mentioned was closely linked to the democracy movement and the goal of equitable access. Portugal and Abrantes note that this goal was operationalized along three lines [28]:

1) Consolidating a comprehensive decentralized system through the harmonization of functions across levels of government through integration of services
2) Empowering authoritative bodies to make decisions about the health system and reach agreements among the involved parties with regard to management
3) Assigning local authorities the responsibility of provision of care to the population of each territorial unit (especially at the municipal level), following the principles of effectiveness and equity.

Figure 1: Organization of Health Care System Pre Reform

Figure 2: Organization of Health Care System Post Reform

Source: Lobato 2000
Consequently, the reforms integrated all public health services under the auspices of the Ministry of Health (MOH), which has primary responsibility for the regulatory and coordination functions of the system [4]. The MOH has direct responsibility for health education, research, tertiary care, and special service delivery (e.g. health care to indigenous populations) as well (Ibid).

Provision of SUS services is carried out by a mixture of both the public and private sector professionals. The municipalities have the ability to utilize purchased services from private contractors to provide care to their respective populations [4]. Organizations that provide contracted services are regulated by the SUS, and priority in awarding contracts is given to philanthropic and not-for-profit organizations [22]. However, the type of services contracted by the government are typically inpatient hospital care, largely in areas where the public sector does not have a tertiary center. For example, 80% of hospitals that provide services within the SUS are private, while 75% of outpatient care occurs in public facilities [28]. It should be noted that, those patients who utilize the SUS, but receive their care in private facilities, are entitled to the minimum package of care provided under the SUS.

The 1988 constitutional reform allows for the continued existence of a private health care sector, which 18-25% of the population (44.7 million people) utilizes in some way. The private sector is comprised of private voluntary health insurance and private providers. Health insurance plans are geographically centered in the southeast portion of the country (around Sao Paolo and Rio de Janeiro) [29]. Typically, anyone with the resources to do so purchases private health insurance. Brazilians may choose among private insurance plans. However, the funds utilized for their public sector care cannot be transferred to private insurance plans, and they retain the right to continue to use the SUS [30]. As a result, some of the population covered by private health plans also use the services of the SUS, especially for complex or costly procedures and treatments (e.g. HIV/AIDS care) [4].

The MOH plays an important role in the financing of the system, but is not the sole source. The SUS is financed with public resources, via taxes and social security contributions, collected from the Federal, District, and municipal governments [4]. At the Federal level, the National Health Fund transfers funds to the states and/or municipalities as either 1) direct payment for services provided to the SUS (e.g. ambulatory care and hospitalization) and 2) fixed “per capita” expenditures for basic health and epidemiological activities [22]. The Federal Government contributes on average half of total funding for the SUS, with the states and municipalities accounting for about a quarter each. However, the total spending and the distribution of funding sources varies by region [4]. A constitutional amendment passed in 2000 established that states and municipalities should allocate 12-15% of their revenues to the SUS, however by 2002, only the municipalities reached this goal [23].

A key aspect of the reform, in keeping with much of the health sector reform movement of the time, was decentralization of the system, with an emphasis on increasing resources and rationalizing the supply and delivery of services [28]. As a result, the SUS operates at the state and municipal level, with the municipalities holding primary responsibility for the provision of health care and services to their populations. They receive technical and financial support from the state and federal governments to do so.
The WHO estimated that in 2006, total health spending in Brazil amounted to 7.5% of the GDP or about US$80.06 billion. Private expenditure accounted for 52.1% of that total, and out of pocket spending by families accounted for nearly 64.0% of private expenditure [14]. Health expenditure per capita was $426, an increase over the 2000 level of $267, with the government paying approximately $204 in 2006 (Ibid). This effectively means that despite universal access to care, individual Brazilians still spend a considerable amount on health.

As a middle-income country, Brazil has also received significant technical cooperation and external financing over the past few decades, including from the World Bank, Inter-American Development Bank, United Nations Development Program, the Pan American Health Organization, and OECD country bilateral cooperation organizations. Funds from these organizations have typically gone to supporting particular initiatives or disease specific projects, such as disease surveillance programs or HIV/AIDS.

Recognizing that the SUS was a work in progress and that further work to define the roles of the various levels of government needed to be done, in 2006 a new “reform” was undertaken known as the “Pact for Life: Strengthening the SUS and its Management” [4, 31]. Focusing on different aspects of the SUS, the Pact essentially establishes a new mode for the overall management of the system and approaches to various national public health problems, placing a greater emphasis on chronic diseases. Overall financing mechanisms were not changed as part of the Pact, but it did result in integration of the various methods of allocating resources. Specific elements, found in the eight volumes, will be discussed in greater detail below.

**Examining Health System Responses**

Understanding how a health system responds to the needs of an individual with a chronic disease is a complex undertaking. The author proposes a new model that may be useful in examining how a health system responds to chronic disease. This model places the individual at the center of an environment of several factors placed in concentric circles extending out from the individual that contribute to his/her health. The factors, ranging from macro to micro include: financing; policy, including prevention policy; service delivery/care, which is shaped by the interaction of workforce, medical products, self-management support; and information technology, which cuts across all levels of influence. See Figure 3. In this model, macro factors are financing & expenditures and policy, and micro factors include those within the sphere of service delivery/care including workforce, medical products, and self-management support. Information technology is simultaneously micro and macro, due to its importance in both spheres.

Financing in this context is defined as the mechanism by which funds are identified, raised, entered, and allocated for health sector activities; how the money is spent is defined as expenditure. Policy encompasses the organization of the health care system, payment system, monitoring and regulation, and the guiding principles resulting in the prioritization of health care issues and programs. Service delivery/care refers to the interface and interaction that occurs at the patient level. This includes the orientation of the care (practice structure), as well as the subcomponents of 1) workforce, 2) medical products (pharmaceutical products and other medical devices/tools), and 3) self-management support (patient/family education, psychosocial support,
including complementary resources in the “community”). Table 3 provides process measures to evaluate the health system response to chronic diseases.

**Figure 3: Proposed Model for Examining Health System Response to Chronic Disease**

![Proposed Model for Examining Health System Response to Chronic Disease](image)

**Table 3: Process Measures to Evaluate Health System Response to Chronic Disease:**

<table>
<thead>
<tr>
<th><strong>Financing and Expenditure</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Source of funding and process for allocation</td>
<td>• % private expenditure</td>
</tr>
<tr>
<td>• Expenditure for disease per person at national level</td>
<td>• % out of pocket expenditure</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Policy</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• National treatment guidelines/protocols</td>
<td></td>
</tr>
<tr>
<td>• Monitoring processes in place (disease status, adherence to protocols)</td>
<td></td>
</tr>
<tr>
<td>• Prevention programs in place</td>
<td></td>
</tr>
<tr>
<td>• Incentive system in place to promote prevention</td>
<td></td>
</tr>
<tr>
<td>• Incentive system in place to promote treatment</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Service Delivery</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Access to care</td>
<td>• Coordinated care (incl. linkage to acute care)</td>
</tr>
<tr>
<td>• Adherence to treatment guidelines</td>
<td>• Regular patient monitoring/testing</td>
</tr>
<tr>
<td>• % of patients on recommended treatment/therapy</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Medical Products</strong></th>
<th><strong>Self-Management Support</strong></th>
<th><strong>Workforce</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Availability of pharmaceutical products</td>
<td>• Patient/family education programs</td>
<td>• Number of specialists</td>
</tr>
<tr>
<td>• Availability of monitoring tools</td>
<td>• Psycho-social support</td>
<td>• Number of non-physician health staff</td>
</tr>
<tr>
<td>• Cost of pharmaceuticals and monitoring tools to patient</td>
<td>• Patients involved in decision-making</td>
<td>• Pre-service training norms</td>
</tr>
<tr>
<td></td>
<td>• Materials/guidelines available to patients</td>
<td>• Opportunities for training post-service</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Health Information Technology</strong></th>
<th><strong>Workforce</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Patient registry system</td>
<td>• Feedback of performance data</td>
</tr>
<tr>
<td>• Epidemiological surveillance system</td>
<td>• Use of information for care management</td>
</tr>
<tr>
<td>• Electronic medical records</td>
<td></td>
</tr>
</tbody>
</table>

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However, the ultimate goal of a health system is to improve health. Health status should be broken into additional disease-specific indicators, when relevant. Table 4 provides health outcome measures for diabetes and HIV/AIDS.

**Table 4: Proposed Disease Specific Indicators of Improved Health**

<table>
<thead>
<tr>
<th>Population level (General, specific at-risk populations)</th>
<th>Diabetes</th>
<th>HIV/AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevalence</td>
<td>Prevalence</td>
<td></td>
</tr>
<tr>
<td>Incidence</td>
<td>Incidence</td>
<td></td>
</tr>
<tr>
<td>Aggregated individual indicators</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% of patients with LDL below 130 mg/dL</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% of patients with HbA1C test in 12 months that was below 7%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% of patients with a CD4 count above 200</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% of patients with a CD4 count above 350</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Health System Response to Diabetes**

**Financing and Expenditures**

In 2007, it was estimated that Brazil was spending approximately US $2.1 billion nationally on care and treatment for people living with diabetes [1]. This figure is expected to increase to anywhere between $3.5 to $6.3 billion by 2025 (Ibid). This figure could also be underestimating the problem, given that the calculation does not take increasing obesity trends into account. While this seems like an extraordinary sum, it does not amount to much per person living with diabetes. In fact, it is less than many other middle-income countries, such as Mexico. In Brazil, the cost of diabetes care for a person with diabetes constitutes about three-quarters of the average per capita expenditure on health, while in many other countries, the cost of care for diabetes is approximating or exceeding the average per capita expenditure on health. See Table 5. This shows how diabetes care is contributing to average per capita health expenditures.

**Table 5: National expenditures for diabetes care and treatment: Brazil, Mexico, and the USA**

<table>
<thead>
<tr>
<th></th>
<th>Brazil</th>
<th>Mexico</th>
<th>United States</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expenditure for care and treatment 2007:</td>
<td>US $2,158,335,000</td>
<td>US $3,461,699,000</td>
<td>US$119,358,449,000</td>
</tr>
<tr>
<td>Number of people with disease</td>
<td>6,913,300</td>
<td>6,115,700</td>
<td>19,157,000</td>
</tr>
<tr>
<td>Average expenditure per person for diabetes care only (expenditure for care &amp; treatment / # of people on treatment)</td>
<td>$312</td>
<td>$566</td>
<td>$6,231</td>
</tr>
<tr>
<td>Average health expenditure per capita (2006)</td>
<td>$427</td>
<td>$527</td>
<td>$6719</td>
</tr>
<tr>
<td>GNI Per Capita, Atlas Method (2007)</td>
<td>$6060</td>
<td>$9400</td>
<td>$45,890</td>
</tr>
</tbody>
</table>


It would be difficult to say, based on these figures if Brazil’s per capita expenditure for a person with diabetes is appropriate or not. Several studies have been conducted to determine the cost-effectiveness of interventions for preventing and treating diabetes in developing regions [1, 32]. Brazil appears to be undertaking the most of the recommended interventions, except some of the most costly, such as covering ACE inhibitors and intensive glycemic control for people with
HbA1c higher than 7%. Brazil, as a middle-income country, has greater resources to devote to help than many lesser-developed countries. However, it’s expenditure on diabetes per GNI per capita is less than that of Mexico; both countries spend less than the USA. Analysis of the effectiveness of the current interventions is warranted before recommending greater expenditure based on simple cross-country comparisons (see section on service delivery/care).

The overall financing structure for health was modified with the 1988 reforms, and has not changed significantly since then. Funds for diabetes care and treatment are drawn from both government resources (through multilevel taxes) and private funding, as described previously. However, it is important to note that Brazilians in general bear an important burden of the cost of their care. Private expenditures have decreased slightly since 1995 (57% of total expenditure on health to 52% in 2006), but out of pocket expenditures still comprise more than half of these expenses (65% of private expenditures in 1995 down to 54% in 2005, but jumping again to 64% in 2006) [33]. This means that on average one-third of total health spending is out of pocket, although expenditures for patients vary state to state [23]. Basic monitoring tools, such as blood glucose meters and strips, are covered in Brazil as part of the national basic package for patients who are insulin-dependent. This can pose a significant out-of-pocket cost to people trying to appropriately monitor their blood sugar but are not on insulin.

Out-of-pocket expenditures due to lack of coverage or availability of medications/tools in the public sector can pose a significant financial risk to individuals living with diabetes and their families. In fact, one recent study found that out-of-pocket payments actually contribute to income inequality for people using the SUS, noting that in the lowest income decile, drugs absorbed 82.5% of out-of-pocket spending [23]. In fact, this same study determined that drug spending represents the largest component of out of pocket payments for all income deciles. If poor glycemic control leads to one of the many related complications such as retinopathy, nephropathy, kidney failure, cardiovascular disease, etc, costs to the individual and the system could escalate rapidly. Once diagnosed, costs for diabetes care will never disappear.

No annual figure for expenditures on diabetes prevention could be obtained for this study. However, the Ministry of Health currently allocates roughly US $32 million for chronic disease prevention activities at the state/municipal level [21]. Financing is drawn largely from government taxes, as mentioned previously, with contributions from the states and municipalities.

**Policy**

The constitutional reform jump-started other health policy and programmatic changes in Brazil. In 1988, the Ministry of Health conducted its first prevalence study of diabetes in the 30-69 year age group, and found a prevalence rate of about 7.6% as previously mentioned [9, 34]. Subsequently, the Ministry set up working groups to implement its first National Program on Diabetes Education to improve treatment and awareness (Ibid). However, these groups were reportedly abolished in the early 1990s.

The reform also led to a strengthening of primary health care as a way to reduce disparities in access to care. In the 1990s, Brazil adopted a frameworks for reorganizing primary care through
a family health approach [28]. The “Piso de Atenção Básica” (PAB) and the “Programa de Saúde da Família” (PSF) were the primary mechanisms to undertake this [4]. The PAB is basically a package of benefits that the municipalities are responsible for providing for the respective populations and for which they are paid on a per capita basis [4, 28]. The Federal Government provides roughly 40% of the funds for the operation of the program (largely the human resource component) [21].

The Family Health Program or PSF, developed in 1994 after the PAB, builds upon this approach through the development of interdisciplinary community health teams, each responsible for a particular area. This program will be discussed in greater detail under the section on “service delivery,” as it plays a critical role in the provision of health services.

However, diabetes was not a major area of emphasis until 2001 when it was addressed in conjunction with hypertension. In 2002, the Ministry of Health of Brazil began to implement a “National Plan for the Reorganization of Health Care for Hypertension and Diabetes Mellitus.” Its aim was to reduce the morbidity and mortality associated with diabetes. The specific objectives of the campaign were to 1) detect suspected cases of diabetes in the SUS through blood testing; 2) support the secretaries of health at the municipal level to connect people with diabetes to the network of basic health services; 3) update professionals in the network of basic health services and the professionals in the PSF program in terms of their care for patients with diabetes based on clinical protocols; 4) improve the availability of drugs for the treatment of diabetes [35]. The effort resulted in about 20 million people (previously undiagnosed) being tested for diabetes nationwide in 2001, with 3.3 million of them being identified as possibly having diabetes (Ibid). This number has increased since the time of this study, as previously mentioned, but no mass screening campaigns such as the one in 2001 have been repeated. The clinical treatment guidelines developed as part of the Reorganization Plan describes self-monitoring of glycemic control as a fundamental part of treatment, but it does not take any steps or offer any methods to facilitate this, such as a strategy to better educate patients around self-monitoring.

In 2006, the National Policy for Primary Care was issued as a component of the Pact. This document defined control of diabetes as a strategic action area, among several other public health problems ranging from Hansen’s disease and tuberculosis to arterial hypertension and oral health [36, 37]. The diversity of issues speaks to the continuing struggle the country is experiencing with their double burden of disease.

Also part of the Pact for Health of 2006 was the publication of the “Guidelines and Recommendations for the Integrated Care of Non-transmittable Chronic Diseases.” While this document describes the integration of various aspects of the health system, it does not address patient self-management support [38]. The document is available on the web and was sent to health professionals throughout the SUS. The Ministry of Health also has developed clinical treatment guidelines that are disseminated in hard copy and on the web for the treatment of diabetes, retinopathy, and the diabetic foot care. The current guidelines were developed in 2006, and a new edition is expected in 2010. They are developed with experts from academia and validated by group of government experts using both efficacy and cost-effectiveness data [21]. One limitation, however, is that there is no monitoring or incentive system instituted to ensure
adherence to these protocols. Training on these protocols or their use is largely dependent on officials at the state or local levels. Some, such as the Family Health Units in Sao Paulo, have centralized training for their health professionals and the staff have time off to receive such training. However, in other areas, such focused dissemination and training may not be occurring.

While diabetes is clearly a growing problem nationwide, historically it has not received the attention or funding by the Federal Government/Ministry of Health that some other diseases, such as AIDS have. This appears to be changing, however. Diabetes prevention and care activities are included under the “Pratique Saude” (Practice Health) program of the Ministry of Health. It is also addressed under other broad health promotion initiatives, such as “Mais Saude” (More Health). The Ministry provides some basic information about diabetes through its website, but there is little information diabetes care (i.e. what living with the disease means to a patient, such as therapies) overall available in that medium.

A National Policy on Health Promotion was published in 2006 as a part of the Pact. This document does not mention any specific diseases, but rather speaks to specific behavioral causes of chronic disease such as dietary habits and physical activity, among others [39]. The document lays out clear responsibilities for each level of government, placing significant emphasis on the states and municipalities. The states and municipalities are expected to implement prevention activities that are aligned with the Policy. However, there is significant diversity in both the amount of prevention funding for each of the states/municipalities, as well as in their selection and prioritization of prevention activities.

Many of the goals are important, such as improved monitoring, training for health workers, and developing intersectorial projects that will improve public spaces. However, there is a lack of discussion in the document about offering incentives to communities, health care providers, or states/municipalities to seriously undertake prevention activities within the context of the SUS. Officials, however, reported that they are now exploring new strategies such as pay-for-performance.

The aforementioned guidelines mention the need for an intersectorial approach. It offers examples of creating healthy, safe public places to facilitate outdoor activities to combat sedentary lifestyle, legislation regarding salt, sugar and fat quantities in food products, laws regarding marketing of unhealthy foods to children, etc. However, none of these activities directly relates to improved patient self-management or literacy for people living with diabetes.

Health education for children in schools is provided in public schools, and children are required to have at least 2 hours of physical activity a week. However, there is little evidence that the curriculum addresses prevention and health promotion activities that would reduce the onset of chronic diseases. The most notable focus for school health programs is on HIV/AIDS and STI prevention.

Screening for diabetes is not standardized for at-risk populations within the health policy. For example, diabetes screening of all pregnant women is not yet a standard. There is a movement to begin screening women at 24 weeks and then refer them to a secondary level care center for follow-up throughout the duration of the pregnancy and postpartum, but this is not yet the norm.
Preconception care for women of reproductive age has been found to be a cost-saving measure in Latin America and in most developing regions. Detecting and monitoring women at risk for gestational diabetes, as well as working closely with those who develop the disease, to manage their glucose levels is critical to maternal health and good birth outcomes. Furthermore, screening seems to be left to the discretion of the health care provider, even in the case of older adults or overweight/obese adults.

Service Delivery/Care

During the early 1990s there was an increase in the number of public diabetes centers in Brazil. However, despite an increase in the burden of disease, no additional centers were established in later years due to the reorientation of care within the country. As previously mentioned, the Ministry of Health initiated a primary health care approach in the 1990s. The Family Health Program, mentioned previously, has often been considered a primary health program. The Family Health Program established teams, comprised of physicians, nurses, nurse assistants, and community health agents and trained in each of the regions, are supposed to provide comprehensive care to approximately 1,000 families respectively. It is estimated that as of 2005, 4,837 municipalities were being serviced by teams, providing care for approximately 73 million people (40% of the population). The program continues to expand, and as of December 2008, it was estimated that roughly 50% of the population or 94 million Brazilians were covered by PSF. Most of the Family Health Teams have been placed in small and mid-sized municipalities with populations smaller than 50,000, in an effort to extend care to medically underserved areas. The states and municipalities have the flexibility to structure the services in a way that best serves their population, including evening and weekend hours.

The emphasis on primary care in Brazil means that most patients will be seen either in traditional health centers or in family health units as their point of entry into the health system. Patients identified here as diabetic will continue to receive their treatment at the primary care level until complications arise. Unfortunately, many people enter the system when they already have complications from diabetes due to lack of early detection. Patients who initiate insulin use are typically referred to secondary level facilities, where many of these teams are increasingly working in an integrated fashion. Some report utilizing a case management approach for difficult patient cases. However, this is not necessarily the norm.

There is a reported lack of sufficient laboratory capacity to provide HbA1C studies for persons living with diabetes, although a specific number of laboratory facilities providing this service could not be obtained for this study. The purchase of this equipment and development of this laboratory capacity falls to the states. There is currently no mechanism to incentivize their prioritization of this lab test and encourage purchase of additional supplies. Another barrier to effective care is reduced availability of care at the secondary and tertiary level. This is due to multiple reasons, including shortage of diabetes experts in the public system, geographic disparities in secondary and tertiary care centers which complicate access due to transportation, employment, child care issues, etc.
Fortunately, the availability of hemodialysis has grown significantly in Brazil in recent years. Experts report that in the past, significant waiting times existed for people with end-stage renal disease requiring hemodialysis. However, now there are sufficient resources nationwide to provide this service to persons requiring this service.

Despite the availability of treatment guidelines issued by the MOH and general improvement in access to care, some studies have indicated that physicians are not adhering to these guidelines and are in need of additional training. For example, one study focused on primary health care centers in Southern Brazil found that nearly three-quarters of patients were taking some sort of medication, including oral hypoglycemic agents, and that many had at least one contraindication [41]. A similar study found that most centers did not meet the basic recommendations of the guidelines, and further suggested that there was an insufficient number of primary health care centers to care for persons with diabetes [42]. Training for health care providers will be addressed in the section on workforce.

Two studies found that the current practices in the primary health clinics managed by municipal governments in the south of Brazil are not conducive to patient adherence to physician recommendations of modifying their diets or performing physical activity [41, 42]. They found that nearly a quarter did not even receive the basic nutritional guidance necessary for diabetes management. Improved communication by health care providers is critical, yet there is no discussion in the Guidelines of utilization of community health workers to improve adherence or the use of group visits to offer support to newly diagnosed patients. Gomes et al have speculated that additional resources for patient education may have the potential to improve the quality of diabetes care [43].

In contrast, unpublished data from a 2008 sample study by the Ministry of Health’s Family Health Program found that nearly 98% of health teams were routinely screening for diabetes and hypertension and prescribing follow-up for those diagnosed [44]. About 83% of the teams were conducting continuous education programs for persons diagnosed with diabetes or hypertension, and about 70% conducted HbA1C testing within 15 days, while another 21% conducted HbA1C between 15-20 days from patient exam. This study did not specifically examine adherence to recommendations, but these practices point to strong adherence. Patient outcomes (e.g. patients meeting treatment goals) were not a part of this study.

A separate multi-center study conducted by Gomes et al found poor metabolic control and health outcomes to be common in Brazil; this was linked to the less intensive clinical treatment available to patients in the SUS [43]. The study included patients from 13 public endocrine clinics from eight Brazilian cities. They found that less than 30% of patients reached blood pressure goals, and only 46% reach the goal for HbA1c levels (Ibid). They noted the significant gap in actual routine diabetes care and care prescribed in the national guidelines. If appropriate interventions are not undertaken as recommended in the guidelines, one must ask what the barriers are to adequate implementation.

Of the estimated 6.9 million people believed to be living with diabetes in Brazil, there is no good estimate for the true number of people who are being followed or are on treatment. The best proxy would be the number entered into the Hiperdia System (which will be discussed in the
section on Health Information Systems) since its inception (1999). Currently nearly 341,000 persons with diabetes have been identified in the Hiperdia System, but that number only includes patients in the public sector who have been entered by health care providers on a voluntary basis.

**Medical Products/Resources**

Oral glucose lowering agents, insulin and tools to monitor glucose are essential for glycemic control. Glycemic control in a population with poor control is cost-savings because of the reduction in acute medical care costs associated with complications is greater than the cost of the intervention [32]. The passage of the PAB mandated that 100 IU of NPH insulin must be provided as part of the SUS basic package of health services to persons with diabetes. However, other medications or monitoring tools were not included at that time. The National Plan for the Reorganization of Health Care for Hypertension and Diabetes Mellitus helped to improve this situation: By October 2005, a law was passed that required the state and municipal secretariats of health to provide a 12 month supply of 850 mg of Metformin and/or 5.0 mg Glibenclamide to persons with diabetes [45] as part of the basic package. Personal glucose monitors and glucose monitoring test strips are available through the Ministry’s public health clinics, but are only free for those patients who have initiated insulin treatment. They are not a standard part of the package for people with diabetes who are only taking oral agents.

The Brazilian Treatment Guidelines encourage early insulinization of patients in order to reduce extreme highs and lows in blood glucose levels, resulting in complications. Analog insulin is expected to be added to the package in 2010 [21]. However, this is of concern among some physicians who believe that patients will be unnecessarily started on analog insulin, costing the SUS a significant amount of money [13]. If the medication is added to the formulary, there are no controls or incentives in place to initiate treatment with less-costly and highly effective therapies such as non-synthetic insulin.

Variations in coverage also exist among the states. For example, the State of Sao Paolo passed legislation requiring the government to provide insulin, other oral medications, test strips, and even insulin pumps ahead of the Federal Government’s inclusion. However, insulin pumps can only be obtained if the patient sues the State to obtain access. Meanwhile, in poorer areas, these tools are often not covered by the SUS, and patients must pay for them out of pocket. This may not be possible for people in lower socioeconomic status (SES). For example, the cost of a glucose test strip in Brazil averages between US $0.50 and $0.80, which would be unaffordable for many people of lower SES. It should be noted that the MOH is the largest single buyer of insulin worldwide [13, 21]. It also procures test strips, but sometimes strips are not even available for purchase within the public health clinics due to poor planning, insufficient funds or supply chain issues [43]. These items are managed by the states and municipalities and are not purchased en-masse by the Federal Government.

One recent study pointed to another type of problem regarding access to diabetes medications. It found that the number of new drugs registered in Brazil between 2000 and 2004 dropped by one-third [36]. The authors note that most new drugs were intended to treat conditions that represented a very small portion of the disease burden, instead of focusing on drugs to treat tuberculosis, hypertension, diabetes, and leprosy, which constitute a much greater portion of the
disease burden. The authors suggest that this disconnect in product development/registration and public health need has been driven by economic interests. However, some physicians argue that many of the new diabetes medications provide no significant medical advancement and are less cost-effective than older medications.

As previously mentioned, there is uneven and inadequate access to HbA1C testing across Brazil. The current treatment guidelines call for this test to be performed four times a year, but most patients are not able to achieve this, given limited access. This is even more problematic if patients are not testing their blood sugar regularly, recording their glucose levels, and providing trend data to their health care professionals for monitoring.

**Self Management Support**

The structural issues of access to care and patient education/literacy have important effects on patient health. Patient education has been identified as an essential component of the interventions necessary to assure compliance with medical and lifestyle regimens for people living with diabetes [32]. However, there is no discussion about the critical element of patient health literacy and education as a first step to better disease management in the guidelines for primary care [39]. The diabetes treatment guidelines speak to the need for modifying diet and physical activity, and it talks about self-monitoring in the context of insulin use to a limited degree [46]. As previously mentioned, tools for self-management, such as blood glucose meters and the test strips they use, are not covered by the basic package of care for patients not taking insulin. There is international debate among diabetes experts as to the benefit of utilizing self-monitoring of blood glucose among patients who have not initiated insulin. Some experts believe that patients who do not have the tools and education to monitor their blood glucose until they are already insulin dependent are at a significant disadvantage because their health has already deteriorated. However, no definitive study has shown this to be the case. Furthermore, the cost of these tools is not insignificant.

Little patient self-management is taught by health professionals within the traditional SUS clinics. At the primary health care level, within typical SUS clinics, there are no diabetes educators to work with patients diagnosed with diabetes. Some primary health clinics employ nutritionists, but significant variation exists across the clinics. There is no systematic education for patients about how to self-monitor their blood glucose or count their carbohydrates to better manage their blood glucose levels. If a patient is referred to a secondary level health center, he or she will likely work with a diabetes educator (typically a nurse) to obtain additional information on self-management. Still, little training is available for patients who wish to log their glucose levels either electronically or in paper form. Lastly, there is no evidence of regular linkages to psychosocial support for patients to enhance their self-management within traditional SUS clinics. For example, one secondary clinic in Sao Paulo did not organize or host group meetings for persons living with diabetes.

The Family Health Program seems to provide better self-management support for people living with diabetes than the traditional primary health clinics of the SUS. The Family Health teams do not include a nutritionist as a standard member of the team, but some clinics where they are based do hire a nutritionist to serve the populations. The Family Health Teams do include community
health agents who help with patient follow-up. If a patient has failed to show up for a scheduled check-up related to their diabetes care or has not picked up their medication, a community health agent will seek them out. The community health agents could play an important role in education of not only the person living with diabetes but also his/her family members by sensitizing them to dietary needs and healthy meals. Many of these Family Health Units have fostered the development of Mutual Assistance Groups. For example, at one Family Health Unit in Sao Paulo, community diabetes support/education groups meet on a weekly basis.

Workforce

Brazil has fewer physicians per 10,000 population than similar countries, and an even smaller number of nurses. There were an estimated 16.4 physicians per 10,000 in 2006, compared to 13.1 in 1995 and 7.2 in 1980; there were 5.5 nurses per 10,000 in 2006 compared to 4.1 in 1997 and 1.9 in 1980 [47, 48]. There does not seem to be any national concern over a physician shortage, but rather there does seem to be concern about distribution. Most practitioners are located within the major metropolitan areas of Sao Paulo, Rio de Janeiro, Salvador, and Brasilia, contributing to disparities in access to care for rural populations [28]. Others have suggested that a shortage of nurses (a four year degree in Brazil) is of greater concern [13].

The number of health workers in the Family Health Program has grown significantly since its inception in 1994. Most notably, the program has developed a huge core of community health agents, lay health workers who are trained to provide health behavior/health education counseling. The community health agent originally started with the identification of local individuals with some standing in the community, an interest in health, and demonstrated literacy. However, the government quickly recognized that a more formal selection process would be needed as the program (and demand) grew. The Congress actually passed a constitutional amendment in 2006 to recognize the community health agent as a real health professional, entitling them to retirement benefits and other social security benefits. This also set the stage for formalized training programs to be established. Currently individuals seeking to become community health workers must undergo training of 400 hours at a technical school. Table 6 shows the number of workers involved in the program.

<table>
<thead>
<tr>
<th>Type of Worker</th>
<th>December 1994</th>
<th>May 2008</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community health worker</td>
<td>29,098</td>
<td>220,080</td>
</tr>
<tr>
<td>Physician</td>
<td>328</td>
<td>27,764</td>
</tr>
<tr>
<td>Nurse</td>
<td>328</td>
<td>28,712</td>
</tr>
<tr>
<td>Dentist</td>
<td>-</td>
<td>16,740</td>
</tr>
<tr>
<td>Dental hygienist</td>
<td>-</td>
<td>1,327</td>
</tr>
<tr>
<td>Other dental assistant</td>
<td>-</td>
<td>16,975</td>
</tr>
<tr>
<td>Other technician or nursing assistant</td>
<td>328</td>
<td>29,071</td>
</tr>
</tbody>
</table>

Moreover, the Family Health Program model has had an impact on medical education programs across Brazil according to government officials. Students who complete their residencies or internships with Family Health Programs are taught with an orientation towards primary care. This increasingly includes education about medical team approaches and case management. However, those who complete their training in traditional medical care settings are not exposed
to this model of care. The traditional SUS clinics/health care centers do not follow this team
approach, but rather work in the traditional, “silo-ed” manner. Pre-graduate training programs in
diabetes care are also largely non-existent.

No national figures on the number of endocrinologists or other health professionals with diabetes
expertise could be found. The Brazilian Diabetes Society (BDS), established in 1970 in Sao
Paolo, appears to be the strongest organization nation-wide dedicated to diabetes, with a
membership of 4000, which may serve as a proxy for total number of clinicians working in
diabetes [49]. The majority of these members are physicians, although there is a small
percentage of nutritionists, nurses, and other health professionals included. The Brazilian
Society of Endocrinology and Metabolism (BSEM) was established in 1950, and its membership
is approximately 2,500 strong. The membership level of the BSEM may also serve as a proxy
for the number of endocrinologists or primary care physicians working in diabetes [50]. Given
the likely overlap of these two organizations, there is likely a shortage of providers nationwide
with adequate knowledge of diabetes care.

Access to post-graduate training in diabetes care varies broadly across Brazil. The National
Program on Diabetes Education of the early 1990s provided some training opportunities. Among
other accomplishments, this program was able to train 7,750 health professionals between 1992
and 2002 in foot examination and foot care, a key component of diabetes care [34]. Neither the
Brazilian Medical Association nor the Brazilian Government require continuing medical
education for health professionals. Some of the societies for specialized medicine require
additional training to maintain membership. The BDS posts training opportunities on their
website, and there have been numerous activities in recent years. However, they do not appear
to be standardized or regular, although there is an annual Congress of the BDS. The BSEM
offers continuing education via online courses, web meetings, scientific meetings, and other
events. These courses are largely focused on theory, not towards application of science and
actual practice.

Additional training for the plethora of primary care physicians who are increasingly providing
care for persons with diabetes is weak, at best. Some pharmaceutical companies provide
additional training, but usually around the use of oral medications and insulin, not on general
patient education, self-management, monitoring, behavior change, or orientation of care to best
serve the diabetic patient. The Family Health Program is an exception: at the regional level, the
Family Health Program provides training for its health care professionals on an ongoing basis at
regional coordination centers[21]. These centers also are charged with disseminating treatment
guidelines and other information from the Ministry of Health.

Health Information Systems

In 2002 the “Sistema de Acompanhamento de Hipertensos e Diabéticos (HIPERDIA or
Accompanying System for Hypertensives and Diabetics) was established by the Ministry of
Health to facilitate the monitoring of risk factors, treatment plans, and medicines. States and
municipalities are required to utilize the system if they want to receive federal funding for
diabetes [51]. The program is downloadable from the Ministry of Health’s website for use at the
local level, and it links to the national database, which provides monthly updated statistics. No
evaluations on how this system has affected patient care or health outcomes have been conducted yet. This system does not track patients at the individual level, but rather gathers population level statistics. Furthermore, the system does not provide a quality check on adherence to treatment guidelines by questioning or rejecting treatment patterns. However, it does serve as a voluntary disease registry.

Strengthening of Health Surveillance Systems was a critical element of the “Guidelines & Recommendations for the Integrated Care of Chronic Non-Transmissible Diseases” published in 2008 as part of the Pact for Health. This document describes how morbidity should be tracked in both hospitals, through the “Sistema de Informações Hospitales” (SIH or Hospital Information System, covering 80% of the country), and in outpatient settings through the “Sistema de Informações Ambulatoriais” (SIA or Ambulatory Information System) [31]. However, these systems do not imply a portable health record for patients within the system that would facilitate truly integrated patient. Rather, these systems function as a national registry.

The Ministry of Health is just beginning to implement the use of electronic medical records across the country. Evidence of this can already be seen in some primary and secondary care health centers, where new computers have been set up and various software packages are being implemented [21].

Families and individuals who seek care at Family Health Units are given paper health cards to help them remember and monitor issues related to their health. The Family Health Units are also in the process of moving to electronic health records, but in the mean time they maintain extensive paper files for patients.

**Health System Response to HIV/AIDS**

**Financing and Expenditures**

The UNAIDS 2008 Report on the Global AIDS Epidemic reported that Brazil spent $565.186 million dollars on HIV/AIDS in 2006 [52]. See Table 7. The largest component of the current expenditures is ARVs, comprising about 78% of the HIV/AIDS budget or $438 million. This constitutes slightly over 1% of Brazil’s total public health expenditure [14, 53]. It should be noted that 99.5% of Brazil’s expenditures on HIV/AIDS are domestic with only 0.1% coming from bilateral donors and 0.3% coming from multilateral organizations.

Brazil was criticized early on for its commitment to provide universal access to treatment for two reasons: 1) the potential for it to lead to drug resistance and consequently a worsening epidemic (a hypothesis which did not materialize) and 2) the cost was deemed unsustainable, particularly for a developing country. It has been able to contain costs through implementation of the Trade-Related Aspects of Intellectual Property Rights (TRIPS) agreement, under which countries can issue compulsory licenses for patented drugs in cases of national emergency. Threat of issuing compulsory licenses resulted in agreements to reduce the prices of many AIDS drugs in Brazil in 2005. The government of Brazil did grant compulsory licensing in 2007 for Efavirenz, which is used by approximately 80,000 patients (38%) on treatment. This led to a reduction in cost from about US $580 per patient per year, representing an annual expenditure of $42.9 million in 2007, to $166 per patient per year, saving the government about $30 million [19, 54].
### Table 7: Cost of HIV/AIDS in Brazil, 2006, 2007, 2008

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Total for Prevention (including some components not listed below)</td>
<td>$34.159</td>
<td>$82.026</td>
<td>$41.759</td>
</tr>
<tr>
<td>Communication for social &amp; behavioral Change</td>
<td>$9.903</td>
<td>$15.221</td>
<td>$16.240</td>
</tr>
<tr>
<td>Community Mobilization</td>
<td></td>
<td>$5.267</td>
<td>$5.514</td>
</tr>
<tr>
<td>Voluntary counseling and testing</td>
<td>$2.455</td>
<td>$8.896</td>
<td>$7.966</td>
</tr>
<tr>
<td>Programs for sex workers &amp; clients; for MSM; harm reduction for IDUs</td>
<td>$0.405</td>
<td>$8.45</td>
<td>$1.647</td>
</tr>
<tr>
<td>Condom social marketing, public &amp; commercial sector condom provision, and female condom</td>
<td>$7.440</td>
<td>$37.915</td>
<td>$9.15</td>
</tr>
<tr>
<td>Prevention of mother-to child Transmission</td>
<td>$5.155</td>
<td>$3.693</td>
<td>$3.799</td>
</tr>
<tr>
<td>Total for Care and Treatment</td>
<td>$470.055</td>
<td>$438.852</td>
<td>$522.611</td>
</tr>
<tr>
<td>Antiretroviral therapy</td>
<td>$438.384</td>
<td>$362.674</td>
<td>$427.758</td>
</tr>
<tr>
<td>Orphans and Vulnerable Children</td>
<td>NA</td>
<td>$36.066</td>
<td>NA</td>
</tr>
<tr>
<td>Total for Program Support</td>
<td>$25.403</td>
<td>$19.691</td>
<td>$22.446</td>
</tr>
<tr>
<td>Total reported domestic public and international expenditure (excludes private sector)</td>
<td><strong>$565.185</strong></td>
<td><strong>$534.962</strong></td>
<td><strong>$623.113</strong></td>
</tr>
</tbody>
</table>

Sources: 2008 Report on the Global AIDS Epidemic, UNAIDS. Country Progress Indicators; Ministerio da Saude do Brasil, Unpublished Data in process for submission to UNAIDS.

### Table 8: Number of Patients on ARVS and Average Cost of ARVs in Brazil

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of Patients</th>
<th>Cost in US$ of ARV/Patient/Year</th>
<th>Total ARV Costs</th>
<th>% ARV Costs/GDP</th>
<th>% ARV Costs/Ministry of Health Budget</th>
</tr>
</thead>
<tbody>
<tr>
<td>1997</td>
<td>36,000</td>
<td>6,222.22</td>
<td>224,000,000</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>1998</td>
<td>57,000</td>
<td>5,350.87</td>
<td>305,000,000</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>1999</td>
<td>64,000</td>
<td>5,250.00</td>
<td>336,000,000</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>2000</td>
<td>79,000</td>
<td>3,835.44</td>
<td>303,000,000</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>2001</td>
<td>90,000</td>
<td>2,577.77</td>
<td>232,000,000</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>2002</td>
<td>105,000</td>
<td>1,704.76</td>
<td>179,000,000</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>2003</td>
<td>139,868</td>
<td>1,377.62</td>
<td>192,684,954</td>
<td>0.038</td>
<td>1.92</td>
</tr>
<tr>
<td>2004</td>
<td>156,670</td>
<td>1,554.84</td>
<td>243,596,783</td>
<td>0.033</td>
<td>1.73</td>
</tr>
<tr>
<td>2005</td>
<td>164,547</td>
<td>1,750.79</td>
<td>288,087,242</td>
<td>0.031</td>
<td>1.63</td>
</tr>
<tr>
<td>2006</td>
<td>174,270</td>
<td>1,830.35</td>
<td>318,975,095</td>
<td>0.027</td>
<td>1.47</td>
</tr>
<tr>
<td>2007</td>
<td>180,640</td>
<td>1,767.75</td>
<td>319,326,360</td>
<td>0.025</td>
<td>1.30</td>
</tr>
<tr>
<td>2008</td>
<td>191,244</td>
<td>1,566.49</td>
<td>299,581,814</td>
<td>0.019</td>
<td>1.08</td>
</tr>
<tr>
<td>2009</td>
<td>186,206</td>
<td>1,608.07</td>
<td>299,432,282</td>
<td>0.020</td>
<td>1.03</td>
</tr>
</tbody>
</table>

When the patent on Efavirenz expires in 2012, Brazil expects to save an additional $236.8 million (ibid). It claims that the use of national generics has cumulatively saved the country more than $1 billion, and that putting people on treatment (and thereby reducing hospital costs) has saved the country more than $2 billion between 1996 and 2004 [19, 55]. For example, between 1997 and 2001, the annual cost of ARVs per patient fell from more than $6000 to about $2600 [56]. See Table 8.

The source of funding for HIV/AIDS programs in Brazil largely comes from the Government of Brazil. Prevention work was largely funded through a series of loans from the World Bank, dating back to 1994. These loans were not to be used in the production, procurement, delivery, or monitoring of ART in Brazil [15]. However, as of 2006, almost all international funding came to an end, and the Government of Brazil assumed about 99% of prevention activities. The cost of care and treatment is financed exclusively by the Government of Brazil and is financed through general taxes as previously described. There is no special carve-out fund for HIV, and patients receiving care have no out-of-pocket expenditures related to lab testing or ART. As ARVs are only permitted to be dispensed by approved public sector health care sites and pharmacies, the cost of HIV/AIDS care in Brazil is almost universally in the public sector.

Interestingly, research related to HIV/AIDS is managed by the National Program for STIs and AIDS, as opposed to through Fio Cruz or other science or health research arm of the Government of Brazil. However, international research teams interested in conducting HIV/AIDS research in Brazil are not required to coordinate with the National Program. CONEPE, the program charged with monitoring such international research, however, does have an informal relationship with the National Program and shares information informally. The research funded and monitored by the National Program is very much driven by the needs of the National Program. Consequently, they generate a significant amount of operational research, in addition to basic science, vaccine, and epidemiological research.

It is conceivable that a person living with HIV/AIDS may seek care with a private physician and pay for care using private funds. However, the ARVs would need to be obtained in the public sector, which would require a consultation with a public sector physician. The only other possible private sector cost would occur in the case of patients purchasing medications for opportunistic infections from a private pharmacy. These medications are planned and procured at the state and municipal level (varying by state who has exact responsibility for which drug), and there have been reports of occasional to frequent stock-outs, depending on the locale. If a person living with HIV/AIDS needed to be hospitalized or receive other care at the secondary or tertiary level, he/she would likely seek care at a SUS facility, as it would be the only kind authorized to manage possible drugs related to HIV/AIDS care.

Given the very low prevalence of mother to child transmission, one might question why so much is spent for prevention activities. The figure reflects largely costs affiliated with counseling and testing, baby formula, medication to inhibit lactation, and some personnel expenses.

**Policy**

Development for HIV/AIDS policies in Brazil came about during an intense time of transition following the dictatorship in Brazil. Civil rights and social equality were hot issues and the
focus for many individuals and organizations; the country reverberated with a sense of advocacy
and reform. Public health fell squarely in the middle of this discussion, along with the
burgeoning HIV/AIDS epidemic. The community touched early by the epidemic was largely
wealthy and educated, and they organized freely during this period. As a result, huge lobbying
for universal access to antiretroviral drugs began almost as soon as they became available. In
fact, a lawsuit was brought against GOB for failure to provide treatment [15].

In 1996, a federal law guaranteeing free universal access to ART was passed. The law states:
“HIV infected people and/or people living with AIDS are entitled to receive from the National
Health System, at no cost, all medicines necessary for their treatment” [57]. The legislation also
stipulates free CD4 cell counts and viral load testing, as well as viral genotyping, when necessary
[58]. It is interesting to note that this legislation does not exclude non-citizens. As a result,
Brazil has been the magnet for AIDS care for immigrants from other countries where they may
not be able to obtain access to care or the same quality of care.

The Ministry of Health has a long history of publishing treatment guidelines for persons living
with HIV/AIDS. The numerous guidelines and recommendations (regularly updated) are
available through the website of the National Program on STIs and AIDS of the Ministry of
Health (www.aids.gov.br). Some credit the establishment of such standards and guidelines as
critical to the achievement of universal access to ART in Brazil. The Federal Government is also
responsible for accrediting health care centers at the primary, secondary, and tertiary level for
treating HIV/AIDS, as well as for surveillance and information management around case
notification, the tracking of ART, and patient monitoring. The states and the municipalities have
responsibilities for the distribution of ART, in accordance with the guidelines provided by the
Ministry of Health. Only public health services can be accredited by the Federal Government to
provide ARVs. Those health centers (outpatient services, clinics, hospitals, etc) wishing to
provide care must apply for accreditation with the Ministry. Approval requires previous
experience working with persons living with HIV/AIDS, adequately trained staff, pharmacy
capacity, and basic laboratory capabilities [15].

The ARV treatment guidelines, consistent with the World Health Organization’s
recommendations indicate that anyone with CD4 count of 200 cells/mm3 should initiate
treatment. Anyone with a CD4 count between 200-350 should be monitored and considered for
treatment. However, the total number of people meeting criteria is unknown, just as the total #
of HIV+ people is also unknown (only estimated).

Prevention activities are shared between the Federal, State and Municipal levels. In fact, more
than 10% of the National Program for STIs and AIDS budget is decentralized to the states and
prioritizes 422 cities [56]. The goal of this approach is to provide flexibility to the local
authorities to tailor planning of prevention programs to the local needs and to finance non-
governmental projects.

The National AIDS Program produces an annual Plan of Actions and Goals (Plan de Acciones y
Metas or PAM) that guides the work for the year and provides a framework for the states and
municipalities. Each of the states, in turn, develops its own detailed PAM to serve as its strategy
for the year. This provides for uniform reporting on indicators for data analysis. The National
AIDS Program publishes yearly updates on progress. Table 9 describes the current focus areas for the national PAM. Each of the state PAMs is available through the Ministry of Health’s website.

Table 9: Focus areas for the 2010 PAM

<table>
<thead>
<tr>
<th>FOCUS AREA</th>
<th>SPECIFIC SUBCOMPONENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Promotion, Prevention, and Protection</td>
<td>a. Strategic prevention inputs</td>
</tr>
<tr>
<td></td>
<td>b. Population segments</td>
</tr>
<tr>
<td></td>
<td>c. Services</td>
</tr>
<tr>
<td>2. Diagnosis, Treatment and Care</td>
<td>a. Adherence</td>
</tr>
<tr>
<td></td>
<td>b. Vertical HIV transmission and elimination of congenital syphilis</td>
</tr>
<tr>
<td></td>
<td>c. Care for viral hepatitis and tuberculosis co-infection</td>
</tr>
<tr>
<td></td>
<td>d. Quality of care</td>
</tr>
<tr>
<td></td>
<td>e. Lipodystrophia</td>
</tr>
<tr>
<td></td>
<td>f. Early detection and treatment of STIs</td>
</tr>
<tr>
<td></td>
<td>g. Diagnosis for Chlymidia</td>
</tr>
<tr>
<td>3. Management and Human and Institutional Development</td>
<td>NOT SPECIFIED</td>
</tr>
<tr>
<td>4. Partnerships with Civil Society Organizations</td>
<td>NOT SPECIFIED</td>
</tr>
</tbody>
</table>

Source: Ministerio da Saude, 2009

Brazil is often hailed for its prevention efforts, ever since it was able to halve its incidence in the 1990s and avoid fulfilling the World Bank prediction of 1.2 million Brazilians living with HIV by 2000. Prevention efforts in Brazil have been largely directed at prevention among the general population, although there are efforts for the most-at-risk populations, including injecting drug users (IDUs) and commercial sex workers [59]. It was able to reduce needle sharing among IDUs through broad harm reduction programs of needle and syringe exchange programs. As a result, IDUs accounted for only 10% of new cases in 2003, compared with 28% in 1993 (ibid). Brazil also increased knowledge and use of condoms among the general population and among commercial sex workers [19]. Currently the National AIDS Program is procuring about 1.4 billion male condoms a year and about 7,000,000 female condoms a year. The condoms are distributed to the states and municipalities per their requested need [21]. Commercial sex work is not illegal in Brazil per se, and as a result, the government has been able to reach this special population more effectively than in countries where greater stigma exists. That does not mean that stigma and discrimination does not affect this vulnerable population, however.

The National STI and AIDS Program’s website provides a plethora of materials on HIV prevention. These materials are directed mostly toward sexual transmission and are updated frequently. For example, in early 2010, a campaign around HIV prevention related to the Carnival celebration was highly publicized. These materials do not reach only the Brazilian population with access to the internet. The National Program produces a number of television commercials, radio spots, billboards, and other media to communicate to the public about HIV prevention. Evidence suggests that these efforts have been highly effective. One study found that between 95 and 98.9 percent of the Brazilians between 16 and 24 years of age knew that using a condom was a way to protect oneself from HIV/AIDS [19].
While the effectiveness of prevention activities for the general population seem to have influenced knowledge and behavior, the program has been criticized for not focusing enough on most vulnerable populations, where the prevalence rates remain high. More directed programming aimed at men who have sex with men (MSM), drug users (not just injecting drug users), and commercial sex workers may do more to curb the spread of the disease. The National AIDS program has attempted to improve care in these populations through work with civil society to try to improve knowledge and sensitivity levels among health workers, as well as reduce stigma and discrimination. The program also partners with civil society organizations to conduct outreach to these groups, who are less likely to frequent health centers for care. In fact, about 10% of the national budget for AIDS is directed toward NGOs and other civil society organizations.

Education around AIDS has also extended into the schools through school health programs in high school. While this has not been without some controversy, the program may have contributed to the increasing condom use among young people [21]. The program, developed in conjunction with the Ministry of Education, tries to increase awareness and knowledge not just among the students, but among the teachers as well, and addresses the issue from a broad health perspective, including alcohol and drug use. International support for HIV/AIDS activities has been directed only for prevention activities. Brazil received three loans from the World Bank for prevention activities, but the funding for these concluded in 2006. Brazil has applied for but not received any funding from the Global Fund to fight AIDS, Tuberculosis, and Malaria (GFATM) for prevention.

**Service Delivery/Care**

As previously mentioned, only accredited public health facilities in Brazil can dispense ART. As of 2007, there were 397 accredited hospitals, 79 day-care hospitals, 58 home-care centers, 422 outpatient facilities, 82 centers for lymphocyte phenotyping (CD4 and CD8), 71 viral load laboratories, and 18 genotyping centers that were engaged in some aspect of AIDS care [56]. As of 2008, the number of viral load laboratories increased to 82, and the number of lymphocyte phenotyping centers increased to 92 [54]. No private pharmacies or health centers can provide ARVs, which assists in overall management/oversight of the AIDS program.

Testing for HIV/AIDS is free to anyone nationwide who chooses to be tested. Testing is offered to all pregnant women (opt out), and as a result the incidence among children under five is very low. Testing involves both pre- and post- test counseling, as a standard. Rapid testing is in the process of becoming the norm, and the National AIDS program is now promoting a mail-in HIV test to encourage testing for those who do not want to test in a medical clinic. In areas with rural or hard to reach populations, some states/municipalities have utilized mobile testing units to increase testing [54]. If a person tests positive for HIV, he/she then receives further testing to determine his/her CD4 count and need to initiate ART.

Unfortunately, as with diabetes, many people are not diagnosed with HIV/AIDS until after complications have arisen. Broader testing efforts, such as expanding testing to more populations identified as most at risk may help address this problem.
After testing positive, a person is referred to a Specialized Care Center (Servicio de Assistencia Especializada or SAE) or Reference and Training Center (Centro de Referencia y Treinamento or CRT). Patients can seek care in whatever SAE or CRT they choose, but they must present their government identification to receive care, as well as their medications. This prevents patients from providing false information to protect their identity out of fear of stigma/discrimination. Some people choose to seek care farther away from where they live or where they would typically go for this reason. Regular primary health care clinics do not carry ARV medications nor do they provide HIV/AIDS related care to PLWHA. This is a problem for PLWHA in more remote or rural areas where access to a SAE is limited. Seeking regular care, albeit monthly or every two to three months, may prove difficult.

The SAEs and CRTs are linked to civil society and offer referrals to mutual assistance/support groups to help with education, adherence, social support, etc. The SAEs and CRTs also offer patient accompanying services with a public sector health professional to help improve adherence among patients who may be experiencing difficulty in adhering to treatment. When a PLWHA becomes ill with a serious infection or complication and requires tertiary care, he/she is referred to a CRT or tertiary hospital, depending on location. If the person has private insurance, he/she may elect to go to a private hospital, but for AIDS related complications, many PLWHA prefer care in the public sector.

By 2003, approximately 125,000 of the estimated 600,000 PLWHA were on ART – roughly 20%. As of 2009, 186,000 people are on ART [60]. See Table 8. The slight decrease in the number of people on treatment between 2009 and 2008 is due to enhanced monitoring and compliance with treatment protocols. As of 2007, it was estimated that roughly 70,000 people were being followed but had not yet initiated treatment, and this number has likely grown [56].

Beginning in 2007, the Ministry of Health instituted a quality control mechanism to evaluate HIV/AIDS care in Brazil. The National Self-Evaluation of Service Quality (Qualiaids) involves a multiple choice questionnaire administered to public health professionals working in HIV/AIDS care and includes recommendations on best practices. No studies of patient perception of quality of care for HIV could be found, but government officials report an interest in funding such research.

Medical Products/Resources

As of 2006, the national formulary for HIV/AIDS treatment included 17 antiretroviral drugs, and 8 of them were produced in Brazil [56]. One recent study found that shortages or stockouts of ARVs rarely occur [61]. These drugs are procured at the Federal level, as previously mentioned. However, the same study found that availability of drugs for opportunistic infections was more problematic. This was independently verified through discussions with various government officials. The responsibility for purchasing these medications falls to the state and municipal governments as part of their overall management of the SUS. Many of the States have developed agreements with the municipalities to determine which level would take responsibility for the management and ordering of which medications. Furthermore, the States are required to report in twice a year to the National STI/AIDS Program about their success in maintaining sufficient medications for the PLWHA population. If a municipality or state fails to maintain
sufficient levels, the program is taken over by the National Program until it is able to
demonstrate sufficient management capacity again. This reportedly occurs very infrequently.

Rapid tests for HIV are not yet the standard across Brazil. They are utilized in ante-natal
screening almost universally. While access to testing in general is not considered an issue, the
government is trying to increase access by promoting the development of Brazilian-made rapid
tests. There are currently two places in Brazil where they are manufactured.

Access to laboratory testing, as previously mentioned, is generally not problematic in Brazil
given the large number of sites. However, some states only have one center for such testing,
which can create delays in obtaining and reporting results. These kinds of delays can affect
quality of care by causing delays in initiation or change in treatment regimens.

Condoms are procured at the Federal level and are distributed to the States and Municipalities,
which further disseminate to non-governmental organizations. For 2010, the Ministry of Health
is procuring 1.4 billion male condoms and 7 million female condoms [21]. The States determine
the need for procurement on an annual basis, and they submit their requests to the Ministry.

**Self-management Support**

As previously mentioned, the Ministry of Health, through the National STI and AIDS Program,
generates and provides a significant amount of public information about HIV/AIDS prevention
and care. Their extensive website contains information in multiple languages about all aspects of
HIV/AIDS from basics about diagnosis, the virus, treatment, adherence, support, nutrition,
human/legal rights, and even complementary therapies ([www.aids.gov.br](http://www.aids.gov.br)). The SAEs and CRTs
offer patient accompaniment services (typically a health worker assigned to follow-up with
patients on a regular basis, offering various forms of assistance from transportation to
psychosocial support) with a public sector health professional to help improve adherence among
patients who may be experiencing difficulty in adhering to treatment. Providers are encouraged
to choose therapies that best fit the circumstances of each patient and will be understandable to
him/her.

This information is augmented by the huge amount of support generated by civil society
organizations. As previously mentioned, SAEs and CRTs offer referrals to mutual
assistance/support groups frequently run by non-governmental organizations (NGOs) to help
with education, adherence, social support, etc. These groups support all elements of the
population: women, children, men who have sex with men, transvestites, drug users, as well as
heterosexual men. Heterosexual men, however, are reported to use these services less frequently
than other groups.

Many of these organizations have created safe houses or “support houses” (Casas de Apoyo) for
individuals who may be separated from their families and have no other place to turn. They
sometimes serve mixed populations, and sometimes they serve specific groups, such as women,
children, etc.
Workforce

As previously mentioned, in the public health system, only accredited facilities are permitted to provide ARVs, and accreditation requires previous experience working with PLWHA and sufficiently trained staff. The Ministry of Health, through its Administration of Education in the Health System, is responsible for proposing and creating policies on the education of health workers at all levels and training professional staff from other related areas to facilitate coordination and integration in the health system [62]. No detailed information could be found on exactly how professionals working in HIV care are screened or how the facilities gain accreditation. Training opportunities and materials related to HIV/AIDS however, can be found through the website of the National Program for STD and AIDS.

The health care professionals in the SEAs and the CRTs employ an integrated team approach to the care they provide for PLWHA. The CRTs, as previously mentioned, are training centers, as well as treatment centers. They not only provide training around advances in therapies and treatment protocols, but they also focus on the reorienting care towards an integrated approach using all members of the health care team, from nurses and doctors to social workers, dentists, nutritionists, psychologists, and even office staff. Combating stigma and discrimination is a central component of training at the CRTs as well.

As previously mentioned, there are fewer physicians per population in Brazil compared to other middle income countries. One recent study found that while in general a sufficient number of physicians are available for basic care, the shortage results in abbreviated appointments to the minimum necessary time, in order to cover the demand for appointments [61]. However, the same study found that about 75% of all sites providing HIV/AIDS care had at least one infectious disease physicians (ibid).

One unexpected finding is that the majority of the employees who serve in the National Program for STIs and AIDS previously worked in civil society in the area of HIV/AIDS, as opposed to other areas within the Ministry of Health. Several government employees indicated that they believed that it was this previous experience, resulting in greater understanding of issues, broad community connections, and orientation of health services, that has contributed to the success of the National AIDS program. Although no number could be obtained for this study of how many employees fit this profile, it is widely believed that the majority do.

Information Technology

The SUS utilizes electronic health records in only a few states, and those medical files are available/transportable between the various levels of care and different health centers. Elsewhere, traditional paper files are kept for patients, which can be a barrier to information sharing, particularly between primary and secondary/tertiary care levels. However, the National Program for STIs and AIDS has developed an advanced system of tracking patients, regardless of their point of entry into the health system that ensures continuity of care as well as contributes to epidemiological surveillance.
Brazil uses four different systems to monitor HIV/AIDS. While this may seem duplicative, they serve slightly different purposes and are able to be cross-utilized to ensure the quality of data. As an infectious disease, AIDS is one of roughly 50 notifiable diseases in Brazil. The system used to notify is known as SINAN (National AIDS Notification System). A person is only entered into the system when his/her CD4 count is less than 350. That is to say, that people who simply have been identified as HIV positive are not entered into this data system until they reach this threshold. The system was first developed in 1993 and has evolved into a a highly efficient system whereby individuals are now entered into this web-based live database using their names, date of birth, and their mother’s name. These identifiers are used to help reduce errors or duplication.

Once a person is diagnosed as HIV-positive, he or she undergoes testing of their CD4 count. This initiates their “entry” or “registry” into SISCEL, the national Laboratory Information System. This system tracks all patients nationwide who have received CD4 testing. There are a limited number of sites that are able to perform this testing, and at a minimum results are returned to the prescribing physician in 15 days. In more rural areas, the results can take as long as 45 days, which can mean an even longer time for patients who have difficulty accessing the health system. This system began in 1995, and the data is collected on an ongoing basis and available to the AIDS programs at the municipal, state, and national level.

As previously mentioned, patients must initiate treatment when their CD4 count drops to 200, but they may initiate with a higher count. Once they start treatment, they are simultaneously tracked by name using SICLOM (Sistema de control de medicamentos), or the Medication Control System. This system provides the ability for a physician to track their patient’s treatment history, as well as for the various levels of government to track the number of people on the various antiretroviral regimens, empowering them in decision-making for planning, budgeting, and purchasing. Because anyone on ART in Brazil must obtain their medications in the public system (no private laboratories maintain ARVs), this system effectively captures everyone on treatment. This sort of tracking system dates back to 1994 when AZT first became available in Brazil. This system also helps detect patients who are not adherent to their treatment through alerts about who has failed to pick up their medication.

Lastly, the SIM (Sistema de Informacion de Mortalidad) serves as the national mortality information system. It also tracks individuals using names and mother’s names when a person passes away with or because of HIV/AIDS.

The epidemiology unit within the National AIDS program collects and can cross-reference the data from the various systems. By using patient names and patient’s mother’s names, duplicates can be removed, improving the quality of the data and providing an accurate picture of the number of people on treatment, their therapies, and epidemiological trends. This information is then published on an annual basis in the “AIDS/STI Boletim Epidemiologico” (Epidemiological Bulletin) and discussed in yearly high-level meetings to strategize for the following year. For example, between 1980 and 2008, the Epidemiology Unit was able to identify 506,499 AIDS cases notified in SINAN, declared in SIM and registered in SISCEL/SICLOM, compared to 432,890 AIDS cases notified only in SINAN for the same period. The different systems help clarify epidemiologic trends; if one were only to examine the deaths, one would think that the
problem is decreasing, when in reality more people are living with the disease because survival has improved.

In addition, the Epidemiology Unit conducts sentinel surveillance with specific populations. Every four years it surveys a sample of 40,000 military personnel, which includes both a behavioral questionnaire and blood testing for hepatitis, syphilis, and HIV. It also conducts sentinel surveillance of pregnant women, nationwide, with a sample of 40,000 women. Finally, it conducts surveillance among injecting drug users and men who have sex with men through a respondent-driven sampling process.

**Discussion**

Brazil is an expansive and diverse country, which clearly poses a challenge to providing health care to the population. However, the Government, through its Family Health Program has been able to expand care to some of the most-underserved areas in the country, in both urban areas (such as the slums known as favelas) and in rural areas. What remains a bit of a paradox, however, is the creation of a parallel health system just for HIV/AIDS care. While Brazil is not unique in creating a separate structure for this disease, it is a bit odd that it would not be integrated into the primary care approach that is so central to the Family Health Program. Perhaps the separation is due to the origins of the epidemic and the strong advocacy for HIV/AIDS care. While this separation may seem to work well in urban areas where there are several sites for people to access care, it poses more of a problem in some of the lesser-developed areas of the country where access to care in general (let alone access to HIV care) is more problematic. If a person is diagnosed with HIV/AIDS in one of the Family Health Units in a rural area, the Unit is unable to provide ART. He/she must seek care at a SEA or CRT, which may or may not be nearby.

It seems that in the interest of improving access to care for more people living with HIV/AIDS that it would be worth developing a pilot program to integrate HIV/AIDS care into some of the Family Health Units in rural or remote areas. The approach to health services provided by the Family Health Units is as integrated as the approach taken in SEAs or CRTs, so it would not be much of a cultural stretch. Rather, health care professionals at Family Health Units would just require some specialized advanced training that could probably be undertaken using distance learning strategies. The Family Health Program already utilizes distance learning to providing continuing education to its professionals.

The orientation of care in both the Family Health Units and within the HIV/AIDS SEAs and CRTs is remarkably similar. Both utilize interdisciplinary teams that work in an integrated fashion to put the patient at the center. The one notable difference is the use of Community Health Agents in the Family Health Program. However, the HIV/AIDS Program has addressed community outreach and patient follow-up through accompaniment programs and linkages with civil society organizations in the place of “lay” Community Health Agents. This may be a more appropriate option, considering the fear of stigma and discrimination that many PLWHA face as well as their concerns over privacy. While Community Health Agents are expected to respect
confidentiality, they typically are members of the small communities that they serve, which can create some difficulties.

The information system in place to track persons living with HIV, ensure appropriate treatment, follow prescription patterns and adherence, and provide accurate information on ARV procurement needs is indeed remarkable. While the multiple systems may, on one level, seem duplicative, they allow the National Program to cross-check the data and obtain a more accurate picture of the AIDS situation in the country. Again, the history of advocacy around the disease, the relatively small population affected, and the need to monitor and control the drugs used to treat the disease facilitated this approach. Some could argue that developing a similar information system for all diseases would be too complicated. Yet, its mere existence suggests that it is not only possible, but that it has resulted in saving and extending the lives of thousands of people living with HIV in Brazil.

Brazil is working on implementing the use of electronic medical records nationwide, which is a massive undertaking that even some of the most “advanced” countries have not been able to achieve. However, the country could learn from its own experience with monitoring HIV/AIDS as it develops a vision for its health information infrastructure. People living with diabetes are not currently tracked and monitored the way people living with HIV/AIDS are, nor are their drug regimens checked and counter checked by information systems and lab results. However, if they were, perhaps people could avoid initiation of unnecessary costly treatments (such as analog insulins). The sheer number of people living with the diabetes may seem unwieldy for health information system developers. However, will the costs and lives saved in the end be worth the investment in such a system?

The lack of urgency around addressing diabetes in Brazil is notable. While many health experts agree that it, along with other frequent comorbidities that accompany overweight and obesity, are on the rise and that multi-sectoral lifestyle interventions are needed to address the problem, it does not appear to have the political or cultural momentum necessary for major activities. It does not have a strong advocacy base the way HIV/AIDS does, although significantly more resources on a national level (not on a per person level) are required to address it (See Table 10).

Table 10: Brazil 2007 Comparison of Disease Burden and Cost

<table>
<thead>
<tr>
<th></th>
<th>Diabetes Mellitus</th>
<th>HIV/AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent prevalence</td>
<td>6.2</td>
<td>0.6</td>
</tr>
<tr>
<td>People living with disease</td>
<td>6,913,000</td>
<td>730,000</td>
</tr>
<tr>
<td>People receiving ART</td>
<td>NA</td>
<td>181,000</td>
</tr>
<tr>
<td>Total estimated expenditure</td>
<td>US $2,158,335,000*</td>
<td>US $534,962,000</td>
</tr>
<tr>
<td>Expenditure for care and treatment</td>
<td>US $2,158,335,000*</td>
<td>US $438,852,000</td>
</tr>
<tr>
<td>Average expenditure per person for Care (expenditure for care &amp;tx/# people on Tx)</td>
<td>US $312</td>
<td>$2,424</td>
</tr>
</tbody>
</table>

Sources: UNAIDS, 2008; Diabetes Atlas, International Diabetes Federation 2008;
*Note: Estimated diabetes expenditures are national and reflect both public and private sectors. However, 80% of Brazilians receive care in the public sector.
Time will tell whether greater advocacy around diabetes will be needed or not. If primary and secondary prevention efforts can be successfully implemented, then the devastating outcomes of advanced diabetes, such as amputation, blindness, and kidney failure can be avoided. The cost of these health conditions is significant and will grow if the disease is not prevented and kept under close control. Brazilian culture places a high value on physical appearance and body size, as well as outdoor physical activities. These cultural norms may help combat the struggle with overweight and obesity, along with the typical associated diseases such as diabetes and cardiovascular disease.

Brazil is significantly more progressive than many other Latin American countries in terms of addressing the needs of some of the most vulnerable and stigmatized populations, such as men who have sex with men, commercial sex workers (gay and straight), transvestites and transsexuals, and injecting drug users. Needle exchange is legal in Brazil and sex work is recognized a legal profession. However, how much is done to serve these communities vis a vis focusing on non-controversial groups like women and children, can vary significantly. Differences are seen across States and Municipalities based on local politics and the influence of conservative groups, such as the Catholic Church. More targeted work may need to be encouraged from the Federal level to slow the HIV/AIDS epidemic in these populations, since the country is truly in the midst of a concentrated epidemic and not a generalized one.

The political environment of the late 1980s and early 1990s in Brazil including the creation of a new government and a new constitution were fundamental to the reform of the health system. The human rights focus that permeated the country during that time led to the widespread belief that access to health care is a right that no one should be denied. This directly drove and shaped the health sector reform that followed. Brazilian health care experts believe that the SUS is a work in progress and that while it’s not perfect yet, they are dedicated to continuous improvements based on the best science and evidence available.
Works Cited


Conclusions

Reviewing the Proposed Model for Examining Health System Response to Chronic Disease

The proposed model discussed above has been very useful in clarifying the strengths and weaknesses of Mexico and Brazil’s public health system responses to HIV/AIDS and diabetes. Conceptually, the overarching components of the framework captured the key components of the responses of each country’s health system with one exception. There was no place in the proposed model to describe the role of civil society or the community. This is an important omission; civil society had been highlighted in other existing models, such as the Chronic Care Model and the Innovative Care for Chronic Conditions Framework. Research in both countries revealed the role of community resources or civil society to be extraordinarily important in the health system response to HIV/AIDS. Similarly, the lack of organized civil society involvement in the response to diabetes should be noted. Accordingly, later in this chapter I propose the addition of a new component in the model for community involvement.

Additionally, the process of working through the model with available country information has revealed a number of lessons about what sorts of additional data could be used as indicators for the various components of the model and which may need further refinement. Specifically, I propose adding the following indicators to better describe the health system response to chronic diseases: the presence of a monitoring system to track and quantify medication stockouts, the number of stockouts per year, number of primary care physicians, number of community health workers, use of multidisciplinary health teams, the number of health team meetings, a formal communication structure among levels of care, the number of staff members with previous civil society/community organization experience now working in government programs, government involvement with civil society/community organizations, and the number of civil society/community organizations actively involved with government.

With regard to medical products, the frequency of government stockouts of required pharmaceutical products or monitoring tools could be measured quantitatively, assuming a consistent definition of a “stockout.” While stockouts of ARVs in Brazil almost never occur, some stockouts still occur in Mexico. Mexico seemingly has few stockouts of diabetes medications, but Brazil seems to suffer from them periodically. In both countries, informal collaboration or arrangements among health centers often allow them to backfill each when there was a stockout so that patients do not have to go without medications. However, these informal backfills typically depend on the existence of strong relationships among health centers. The development of a system to required reporting of shortages would provide greater assurance that patients would never lack crucial medications, and the frequency per year could serve as a good indicator of availability.

With regard to workforce, obtaining the number of primary care or family physicians would be useful. While the number of physician specialists is an important number to determine the availability of providers with advanced knowledge for complicated patient cases or difficult acute care episodes, increasingly it is the primary care physician who is providing care to persons living with HIV and persons living with diabetes. Determining the readiness of these physicians to appropriately treat these patients is also critical. Have they been able to receive appropriate training to serve the population in question? Another possible indicator that could be viewed as
a component of “number of non-physician health staff” is the number of community health workers.

Effective communication among the various providers of healthcare who touch the lives of patients is critical. The proposed model did not include a specific indicator to capture this explicitly, although it is shown in the graphic representation. The instances where health teams were utilized in both countries, CAPACITS and UNEMES in Mexico and a the Family Health Units and CRTs/SAEs in Brazil, team meetings and other regular methods to communicate regularly (improved medical record keeping, emails/notes to other providers, etc) were essential to effective communication. It enabled providers to not only ensure clear treatment paths, but it also enabled them to gain a better understanding of issues the patient was facing. For example, in Brazil, patients frequently shared more information about their personal situations (family, employment, other social issues, etc) with community health agents than with other providers. This information was frequently shared by the health agents with the rest of the family health team during meetings and was used to better adapt treatment to the patients’ needs.

Communication among health team members, which could be considered “horizontal integration,” is at the heart of the concept of multidisciplinary health teams, and extends to community resources that support patients and their families. One way to measure effective communication would be to describe if multidisciplinary health teams being utilized and quantify their meetings per week, month, or year.

In both countries, better communication between primary/chronic care services and acute care services, sometimes referred to as “vertical integration,” could improve patient outcomes. In both countries, communication could break-down when a patient required acute care at a tertiary level (unless the system was entirely “closed” meaning a site provided in situ primary, secondary and tertiary care, such as some CRTs in Brazil). While electronic medical records are just being implemented in the Brazilian SUS, they will enable smoother communication between various levels of care; this is far from a reality in Mexico. In both countries, the channels of communication are not sufficiently formalized to facilitate direct communication (e.g. phone calls, emails, or in-person meetings) between primary care providers and the tertiary care providers who may see an acutely ill patient.

The complexity of the variables affecting chronic care often requires face-to-face communication among the various providers touching the patient’s life. Though it may seem counter intuitive however, emails or a phone call between primary and tertiary providers may suffice because the complexity of the acute health care situation may remain almost entirely in the domain of the tertiary provider. The number of people involved in chronic care may make horizontal communication among providers more complex and hence more interdependent, resulting in the need for face-to-face communication. Similarly, the acute care team may also need to have regular communication because of the complexity it faces in providing care. However, the communication between the two levels may not need to be all that sophisticated. This would be consistent with James Thompson’s discussion of coordination and interdependence, where each team would be considered “technical” and closed [1].

This problem is not unique to Mexico and Brazil, but rather is seen in many high income countries with supposedly “advanced” health care systems. Portability of electronic medical
records to different levels of health care might serve as an indicator to track the component of health information technology. Description of communication patterns between health care providers of different levels (primary, secondary, tertiary) would complement this information.

Thinking about the role of civil society and other community organizations in the model, quantifying the number of staff members in the federal level program offices for each disease who have come from these types of organizations might be a start. Learning from Brazil, most of the staff working at the National AIDS and STI Program previously worked in civil society organizations. Staff credited having this experience as critical to the success of the program because 1) they understood how civil society organizations worked and where; 2) they often had greater knowledge of issues related to HIV/AIDS, particularly from a patient perspective; 3) they had ongoing relationships or connections with those organizations that kept the dialogue open and could inform future decisions; 4) it makes the civil society organizations more willing to work with the government. Another aspect would be to qualitatively describe the involvement with civil society or community organizations. The number of civil society organizations actively involved with government (federal, state municipal) could also be used as a quantitative indicator.

These reflections lead me to propose a modified model for future use. In the revision, I add a new layer called “Community Involvement” between the levels of “Governance/Policy” and “Service Delivery/Care.” I designate this component as a macro factor (in yellow), as community or civil society organizations are not linked to service delivery and care but often play multiple roles, including advocacy at the policy level, and can often be multifaceted, interfacing with other sectors like transportation, environment, or housing. See Figure 1.

**Figure 1: Revised Model for Examining Health System Response to Chronic Disease**
The additional indicators contemplated, as well as the modifications discussed above are presented in Table 1.

### Table 1: Revised Indicators to Evaluate Health System Response to Chronic Disease

<table>
<thead>
<tr>
<th>Financing and Expenditure</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Source of funding and process for allocation</td>
<td>% private expenditure</td>
</tr>
<tr>
<td>• Expenditure for disease per person at national level</td>
<td>% out of pocket expenditure</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Policy</th>
</tr>
</thead>
<tbody>
<tr>
<td>• National treatment guidelines/protocols</td>
</tr>
<tr>
<td>• Monitoring processes in place (disease status, adherence to protocols)</td>
</tr>
<tr>
<td>• Prevention programs in place</td>
</tr>
<tr>
<td>• Incentive system in place to promote prevention</td>
</tr>
<tr>
<td>• Incentive system in place to promote treatment</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Community Involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Number of staff members coming from civil society/community organizations now working in government program</td>
</tr>
<tr>
<td>• Government involvement with civil society/community organizations</td>
</tr>
<tr>
<td>• Number of civil society/community organizations actively involved with government</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Service Delivery</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Access to care</td>
</tr>
<tr>
<td>• Adherence to treatment guidelines</td>
</tr>
<tr>
<td>• Regular patient monitoring/testing</td>
</tr>
<tr>
<td>• Use of multidisciplinary health teams</td>
</tr>
<tr>
<td>• Frequency of team meetings</td>
</tr>
<tr>
<td>• Formal communication structure among care levels</td>
</tr>
<tr>
<td>• % of patients on recommended treatment/therapy</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Medical Products</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Availability of pharmaceutical products</td>
</tr>
<tr>
<td>• Availability of monitoring tools</td>
</tr>
<tr>
<td>• Cost of pharmaceuticals and monitoring tools to patient</td>
</tr>
<tr>
<td>• System to track stockouts</td>
</tr>
<tr>
<td>• Number of stockouts per year</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Self-Management Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Patient/family education programs</td>
</tr>
<tr>
<td>• Psycho-social support</td>
</tr>
<tr>
<td>• Patients involved in decision-making</td>
</tr>
<tr>
<td>• Materials/guidelines available to patients</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Workforce</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Number of specialists</td>
</tr>
<tr>
<td>• Number of primary care physicians</td>
</tr>
<tr>
<td>• Number of non-physician health staff, including community health workers</td>
</tr>
<tr>
<td>• Pre-service training norms</td>
</tr>
<tr>
<td>• Opportunities for training post-service</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Health Information Technology</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Patient registry system</td>
</tr>
<tr>
<td>• Epidemiological surveillance system</td>
</tr>
<tr>
<td>• Electronic medical records and their portability among health care levels</td>
</tr>
<tr>
<td>• Feedback of performance data</td>
</tr>
<tr>
<td>• Use of information for care management</td>
</tr>
<tr>
<td>• Communication between health care providers of different levels</td>
</tr>
</tbody>
</table>

With regard to overall health system performance indicators, no additional modifications are offered at this time. They are found in Table 2.

### Table 2: Proposed Disease Specific Indicators of Improved Health

<table>
<thead>
<tr>
<th>Diabetes</th>
<th>HIV/AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Population level (General, specific at-risk populations)</strong></td>
<td></td>
</tr>
<tr>
<td>Prevalence</td>
<td>Prevalence</td>
</tr>
<tr>
<td>Incidence</td>
<td>Incidence</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Aggregated individual indicators</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>% of patients with LDL below 130 mg/dL</td>
<td>% of patients with a CD4 count above 200</td>
</tr>
<tr>
<td>% of patients with HbA1C test in 12 months that was below 7%</td>
<td>% of patients with a CD4 count above 350</td>
</tr>
</tbody>
</table>
Comparing Mexico and Brazil

ARVs

One of the notable findings from this study was the difference in pricing of ARVs between Mexico and Brazil. The differences have been documented elsewhere, and the reasons behind them seem to be: 1) Brazil’s own national pharmaceutical industry, 2) Brazil’s invoking of the TRIPs agreement and use of compulsory licensing, 3) Mexico’s delicate political relationship with the United States and its pharmaceutical industry, and 4) possible restrictions contained within the North American Free Trade Agreement (NAFTA). It is beyond the scope of this paper to explore these further. However, lessons from Brazil’s experience may be of use to Mexico in its efforts to obtain lower ARV prices.

By centralizing the response to HIV/AIDS in Brazil and not allowing private practitioners to dispense ARVs, the Brazilian Government has complete control over purchasing and distribution. Part of the problem in the Mexican environment until recently was that each of the branches of the Mexican government were negotiating separately with the pharmaceutical industry. By passing a law to centralize the purchase of ARVs for all government agencies, the Government of Mexico gained tremendous negotiating power.

Using secondary data, I have estimated that Mexico was able to drop the cost per patient for ARVs for one year to about $3400 in 2009. While this is a big improvement over the previous cost of about $5000 in 2007, it is still about $1000 per patient per year more than Brazil pays. In Brazil, the only buyer of ARVs is the government; there is no private sector involvement. The private sector providing HIV care in Mexico is quite small, and it is not clear how much negotiating power could be gained by the government by trying to shut it down.

The private sector also serves as a backup system for patients when their public sector facilities face shortages. Limiting the capacity of the private sector to fill gaps by removing this backup system would be detrimental to people living with HIV/AIDS, even if it could somehow lower excessively high prices. So, how can Mexico get the per-patient cost for ARVs to come down further? Certainly further annual or biannual negotiations with ARV manufacturers at the national level should be continued.

Another approach would be for Mexico to gain efficiency by ensuring that the medications dispensed are appropriate. This would only be possible with an enhanced patient and medication monitoring system that would span all public health systems. It could serve as a mechanism to ensure provider adherence to treatment guidelines, and reduce the prescription of costly second-line medications until medically necessary. This idea could face significant political opposition because of the strong sense of autonomy felt by each institution.

In addition, a unified electronic system for reporting the dispensation of ARVs across all government health systems might solve another problem in Mexico. It could reduce redundancy in purchasing and dispensation by tracking patients more closely. Currently patients may “game the system” by seeking care in both IMSS and SSA, using whichever may be easier to access at the time. Since IMSS and SSA register patients and order/Dispense medications separately,
patients who simultaneously seek care in both systems cannot be identified. Tracking patients with a universal number, such as a national identification number (which is used in Brazil), would solve this. However, in Mexico, individuals are not issued a universal identification number that could be tracked across all systems. People who use IMSS have a social security number issued to them at their first instance of formal employment. In comparison, people who have never worked in the formal sector (granting them a social security number) or have never registered to vote (granting them a voter identification number, which is the most common form of identification in Mexico), may not have any number whatsoever. While not foolproof, the easiest number to use is likely the voter identification number, as that is required in most institutions and places of business (e.g. banks) as a proof of identity.

If patients and their medications were tracked and dispensed using a voter identification number in a live electronic system, duplications could be eliminated, making the systems more efficient. This could lead to other opportunities, in years to come, to improve access. For example, this unified system could allow patients to receive their ARVs at any pharmacy of any public health system in Mexico. By tracking the site of dispensation, the various systems could then reimburse each other quarterly or annually for any patients crossing systems. This is probably as close to a unified system for AIDS care that Mexico will ever get because of the strong institutional histories of the various systems.

The high cost of ARVs, regardless of price negotiations, relative to the cost of diabetes medications or even basic antibiotics for opportunistic infections, has raised questions in the past about the sustainability of the governments’ commitments to providing universal access to ARVs. Mexico’s unique approach of developing a Fund for Catastrophic Expenditures effectively carves out the cost of ARVs for the SSA’s Seguro Popular Program, thereby protecting individuals from financial ruin, as well as the SSA budget so that other critical activities, such as prevention and extension of services, could be maintained. While this carve out may not be necessary in the Brazilian system because the SUS has access to greater revenue because of taxes imposed on employers (in Mexico, IMSS enjoys this benefit while SSA does not), this model may work well in other countries where there is more than one public health system in place and risk pooling is necessary.

**Primary Care Approaches**

The second chapter of this study discussed the various forms of “integration” in health care and the role of integration in providing care to those living with chronic diseases. The Institute of Medicine considers integration a key component of primary care and has been defined as “comprehensive, coordinated, and continuous services that provide a seamless process of care” [2]. They define primary care as “the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health needs, developing a sustained partnership with patients and practicing in the context of family and community” [2]. This definition defines the care provided by the Brazilian SUS through its CRTs and SEAs and the Mexican CAPASITS for HIV/AIDS. They are the first place of entry into the health system for people with HIV/AIDS and the center for all of their care until or unless they require secondary or tertiary care. Primary care is also at the heart of the Family Health Program of the Brazilian SUS.
The aforementioned definition of primary care also proposes a paradigm shift of curative care to continuous care. It alludes to “continuous services” and “sustained partnership,” both of which would play a role in the management of chronic diseases. In fact, Julio Frenk, in a recent article titled “Reinventing primary health care: the need for systems integration,” wrote: “Primary health care should also move from episodic to continuous care, going beyond the simplicity implied in the original notion of first level of care” [3]. This has dramatic implications for many health care providers who may have been trained from a curative perspective. Chronic disease translates into chronic contact with the health care system, which means more patient visits. Hence, providers may need assistance in understanding what this means and how to better orient the care they provide to maximize the increasing demands placed on their time. Multiple solutions exist, ranging from increased use of community health workers and increased utilization of other non-physician professionals (frequently called “task shifting”), to group medical visits (where several patients meet with a provider at a time, generally for education session) and the utilization of a health team approach.

A team approach to managing chronic diseases has been hailed as a solution to manage the increase demands on physician time in primary care settings [4]. It also increases access to care for patients because a patient’s needs could be handled by one or more of the team members, depending on the care issue he/she faced. Teaching health care providers how to work in team can begin as part of pre-graduate training, but can also be provided through post-graduate interventions, as Brazil has shown. The team approach is at the center of the Family Health Program in Brazil, which has already demonstrated success in chronic disease care, particularly diabetes. Furthermore, it has been crucial to extending primary care services in previously underserved areas, such as rural parts of the country or within urban slums. This model could be a far better investment for Mexico to implement than creating UNEMES for chronic disease. Chronic disease does not need to be managed in a stand-alone clinic.

Chronic diseases are managed in a primary care setting all the time. But, they key to successful management of these diseases is that the health teams of the primary care setting have the knowledge and skills to do so. In the case of HIV/AIDS, those primary care teams should have advanced training or experience with HIV/AIDS care and its related comorbidities and psychosocial sequelae. Brazil requires such training or experience, but neither Mexican health system studied here requires it. Training of health professionals around diabetes care is generally weaker in both countries, despite the significantly greater burden of disease. While both countries are making efforts to educate their health care professionals, a huge need still exists if patient care is to be optimized. This does not create an argument for carving out diabetes care the way HIV care has been handled in both countries. On the contrary, the epidemic of the diabetes, related cardiovascular disease, and their sequelae speak to the need to educate broadly in all primary health care settings.

So, this then begs the question of whether HIV/AIDS care should be integrated into primary health care centers in both countries or whether it should remain stand-alone? Stand-alone sites require a significant amount of resources. Yet, is broad training in HIV/AIDS care a good use of resources when the number of people affected is relatively small? In the case of Brazil, it does not make much sense that a person living with HIV/AIDS who resides in a rural area has to travel several hours to a SEA or CRT to receive care, instead of visiting their local primary
health center (be it a State/Municipal run center of a Family Health Program site). Perhaps in areas of low population density, HIV/AIDS care could be integrated into general primary care health centers with special training for the health care professionals who work there. This would help improve access for patients.

**Health Care as a Right**

The active engagement of civil society in the HIV/AIDS arena has been critical in both Brazil and Mexico to achieving government commitment to universal access to ARVs. Brazil made the commitment in 1996, while Mexico did not do so until 2003 (Indeed ARVs did not even become standard care in Mexico until 1998, far later than Brazil). The Brazilian epidemic came into force during the peak of huge political change in the country, where civil rights, including the right to health care were front and center. The strong move toward democratization, coupled with demand for transparency and equality enabled the huge reform to the health sector that resulted in the development of the SUS. Just a few short years later, access to ARVs was viewed as an obvious component of the newly established rights, and civil society would not accept any other reality. In fact, so strong is the belief around the right to health in Brazil that the country does even provide health care services or costly medications such as ARVs to non-citizens.

A constitutional amendment in Mexico similarly made health care a right in that country. However, there was no similar upheaval in government at the time that enabled massive structural change: the massive social security giants would not be moved. So, incremental changes to expand health care coverage ensued over the following decades. Still, it was a firm belief in the constitutional change that empowered civil society to demand fulfillment of their rights when it came to HIV/AIDS care. By 2002, many other countries had committed to providing universal access to ARVs, and HIV/AIDS activists in Mexico and from the international community were able to leverage lessons from other countries and mobilize effectively to fight for ARVs.

In both countries, the civil society remains deeply engaged in the processes around HIV/AIDS prevention and care. There is a strong sense of civil rights and social justice that provided the foundation for activism around the disease. In comparison, however, there is no movement in either country with the strength or numbers to draw attention to or resources for diabetes prevention and care. Is it because HIV/AIDS was initially a dramatic and quickly lethal disease? Was it because it initially affected some well-educated and middle-to-upper class populations that could draw attention to their plight and generate resources? Is it because people knew it was linked to sex, and therefore almost no one would be immune? Everyone loves sex. Nobody wants sex to kill.

But, then there is diabetes, affecting so many more people. Although it will not kill as quickly as AIDS, it can kill slowly and painfully. It initially affected middle-to-upper class populations because they had more access to food, and consequently had more opportunity to become sedentary, overweight, or obese. It was linked to food, and everyone needs to eat. Everyone loves food. Nobody wants food to kill.
Final thoughts
Sex and food: two things that everybody loves. Sex and food: two things that if handled without proper care can kill you, sooner or later. Sex and food: two things that can wreak havoc on health systems. This study was intended to examine how two countries were dealing with the consequences of sex and food, indirectly. HIV/AIDS in Brazil and Mexico is largely transmitted through sexual contact. Type 2 diabetes is, in most cases, directly related to overweight and obesity, a heavy burden (pun intended) in both of these countries.

HIV/AIDS and diabetes: two preventable diseases. A cure for these two deadly diseases still eludes scientists, but the means to prevent their spread are well known. Public health systems can and must focus on prevention as well as care. A health care system is not a health care system if it only focuses on illness; that would be called a “sick care system.” A health care system must try to keep people chronically healthy, not just try to make them healthy when they are sick.
References


