A Review of Diabetes Treatment Adherence Interventions for the Eastern Caribbean

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Abstract

Objective: Systematically analyze previous research pertaining to the monitoring of adherence to diabetes medication, identify barriers to patient compliance, and examine possible intervention models dealing with this public health burden in the Eastern Caribbean.

Search Methods: Literature was reviewed for meta-analysis using PubMed and Google Scholar searches. Information was included from Web site searches on the American Diabetes Association, the World Health Organization, the Pan-American Health Organization, and the Caribbean Health Research Council Web pages in March 2012. Article inclusion was restricted to English language articles published in or after 2004; many articles were included due to lack of academic coverage of the subject. Major contributing journals included *Diabetes Care, the West Indian Medical Journal, Diabetic Medicine, Quality in Primary Care,* and *Primary Care Diabetes.*

Main Conclusions: While good work has been published on the barriers to treatment and intervention models to support diabetes compliance in the Caribbean, there are many efficacious non-Caribbean models that could be culturally tailored and applied in the Eastern Caribbean for better diabetes outcomes.

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PART 1
Review of Diabetes Mellitus Epidemiology, Cost Burden, and Guidelines in the Caribbean

EPIDEMIOLOGICAL REVIEW OF DIABETES MELLITUS IN THE CARIBBEAN

The Lesser Antilles region of the Caribbean describes six sovereign states: Antigua and Barbuda, Commonwealth of Dominica, Grenada, St. Christopher (St. Kitts) and Nevis, St. Lucia, and St. Vincent and Grenadines. Health statistics are limited for these Eastern Caribbean nations due to lack of resources, including personnel, existing survey infrastructure, and funding available for non-communicable disease monitoring. Therefore, for the purposes of this literature review, articles were drawn from global studies relying heavily on the work of Adams and Carter (2010; 2011a; 2011b) in Barbados, as well as several articles from Trinidad and the *Journal of Western Indian Medicine.*

Today, the Caribbean nations face increasing pressures to quickly industrialize and develop. With moderate levels of geographic mobility, improved technology, as well as a burgeoning tourism industry, people in the Caribbean are exposed to more of the non-Caribbean world (Boyne, 2009). With these population-level transitions, the face of health challenges in the Caribbean is also shifting. The Caribbean is experiencing the double burden of communicable and non-communicable disease, meaning infectious disease such as HIV/AIDS exists simultaneously with chronic disease, such as diabetes (Albert et al., 2007). Diabetes mellitus is defined by the World Health Organization (WHO) as a "metabolic disorder characterized by chronic hyper glycaemia with disturbances of carbohydrate, fat, and protein metabolism resulting from defects in insulin secretion, insulin action, or both" (Alberti & Zimmet, 1998). Caribbean residents are known to be at high-risk in general for diabetes acquisition. Of people living with diabetes in the Caribbean, 95% of cases are Type 2, and only 5% have Type 1 diabetes (PAHO & CHRC, 2006). Although Type 2 is far more prevalent, studies on Type 1 diabetics can also be used to inform risk factors and treatment barriers for Type 2 diabetes. Risk factors for diabetes, include *modifiable* (diet, physical activity) and *non-modifiable* (age, gender, ethnicity) risk factors (WHO, 2003b). Modifiable and non-modifiable risk factors specific to Type 2 diabetes in people living in the Caribbean are shown below in figure 1.

Risk factors such as obesity have increased among all Caribbean populations. From 1976 to 2006, obesity rates among preschoolers in St. Lucia have tripled (Gardner, Bird, Canning, Frizzel & Smith, 2010). Youth are particularly at risk as the incidence of early onset Type 2 diabetes among youth steadily increases. Studies in Jamaica reveal that although Type 2 prevalence is low among 15-19 year olds, issues of anxiety and inability to find resources are found to affect youths' quality of life and increase severity of disease. Moreover, youth are the least likely age group to adhere to strict medical regimens, such as diabetes treatment (Tulloch-Reid & Walker, 2009; Tulloch-Reid et al., 2010).

Figure 1. Modifiable and Non-modifiable risk factors for Type 2 Diabetes in the Caribbean

Modifiable Risk Factors for Type 2 Diabetes	Overweight (BMI ⌖25 kg/m2)
	Physical inactivity
	Lifestyle factors
	Low HDL-C or high triglyceride levels
	Coronary artery disease, hypertension, other vascular complications
Non-Modifiable Risk Factors for Type 2 Diabetes	Age 45+
	Diabetes in first-degree relative
	Prior gestational diabetes or history of delivering a baby >4 kg (9 lbs)
	Polycystic ovary syndrome
	History of Impaired Glucose Tolerance (IGT) or Impaired Fasting Glucose (IFG)
	Asian or African descent

Source: PAHO & CHRC, 2006

The Caribbean countries are the hardest hit areas in the Americas in terms of chronic disease; in fact, diabetes specifically was among the top four leading causes of death in Caribbean countries from 1985 to 2000 (Cunningham-Myrie, Reid & Forester, 2008; Ferguson, Tulloch-Reid & Wilks, 2010). The Caribbean Epidemiology Center assembled data on leading causes of death for women and men in the Caribbean Community (CARICOM) nations, also showing increases in diabetes-related mortality from 2000 to 2004 (CAREC & PAHO, 2007). Diabetes was identified as the major mortality risk factor for women older than 60 years in Tobago, attributing to 28% of deaths (Molokhia, Nitsch, Patrick & McKeigue, 2011). The Pan-American Health Organization (PAHO) found in 2009 that diabetes-related mortality ranges in the Eastern Caribbean from 26.2 deaths per 100,000 in St. Kitts and Nevis, to as high as 130.8 per 100,000 in Antigua and Barbuda. PAHO also provides the adjusted U.S. mortality rate of 16.2 per 100,000 individuals (PAHO, 2009). The striking difference between mortality rates calls for an investigation of diabetes mechanisms at work in the Eastern Caribbean.

COST BURDEN OF DIABETES IN THE CARIBBEAN

Non-communicable disease (NCD), such as diabetes, can be a huge economic burden to a country not receiving outside aid for NCD programs (Hospedales, Samuels, Cummings, Gollop & Greene, 2011). One study estimated the costs of diabetes in Latin America, including the English-speaking Caribbean in 2000 and found that direct costs attributed to diabetes amounted to U.S. $687 per capita, compared to U.S. $528 per capita in Mexico. Overall costs—direct and indirect—to the region amounted to U.S. $1030.5 x 10^6 (Barcelo, Aedo, Rajpathak & Robles, 2003). Another review of cost analysis studies in the U.S. suggests that non-adherence itself is an economic burden (Breitscheidel, Stamenitis, Dippel & Schoffski, 2010). The Caribbean specifically experiences high loss of human workforce capacity compared to other regions due to complications of diabetes, such as diabetes-related amputation. One study found that the five-year survival rate for diabetic amputees was only 44%, compared to 82% among the control group of non-amputee diabetics (Hambleton et al., 2009). Another study in Barbados found that this high rate of diabetes-related amputation was due to inadequate footwear (inadequate footwear triples the risk of amputation). Researchers suggested increasing patient and professional education concerning footwear and foot care for diabetic individuals (Hennis et al. 2004).

Diabetes is burdensome for an already struggling health care system in the Caribbean; indicators of economic strength by country are shown in Table 1, including unemployment rates, health facility information, existence of NCD policy, as well as percentage of Internet users. With the highest population estimate of 162,178 people (St. Lucia) also has one of the highest unemployment rates (20%) in the Eastern Caribbean, as well as the highest percentage of internet users (88.5%). On the other end of the continuum, St. Kitts and Nevis, with the smallest population estimate of 50,726, has the lowest unemployment rate of about 5%, and the smallest number of health facilities. Grenada reports the lowest internet use of 32.2%.

Table 1. Demographic and Epidemiologic Characteristics of Six Caribbean Nations

Country	Population Estimate (1)	GDP per capita (US dollars) (2)	Number of Health Facilities (3)	Diabetes Mellitus Mortality per 100,000 (4)	Internet Users % (5)
Antigua & Barbuda	89,000	$13,000	34	42.7	80.8
Dominica	73,000	$6,000	55	38.7	44.1
Grenada	109,000	$6,000	45	91.8	32.2
St. Kitts & Nevis	51,000	$11,000	22	77.2	44.4
St. Lucia	162,000	$6,000	40	45.4	88.5
St. Vincent & Grenadines	104,000	$5,000	59	62.5	73.2

Notes: (1, 4) Adjusted rates from PAHO 2012 Basic Indicators; (2) 2010 Word Statistics Pocketbook; (3) Health Systems 20/20 and SHOPS data, include general hospitals, health centers, rural hospitals, private hospitals, mental health centers, geriatric homes, public/private laboratories, and outreach health centers; (5)www.internetworldstats.com/stats11.htm, data from Dec 31, 2011

Across the board, the Eastern Caribbean is currently battling weak enforcement of NCD regulation and guidelines, as well as a lack of coordination between health-related agencies resulting in low efficiency. Another cross-cutting theme among countries was the increasing construction of secondary and tertiary facilities, while simultaneously preserving primary care facilities. This balancing act will require scrupulous planning and oversight of financial resources (Health Systems 20/20 & SHOPS, 2012a-e). These political and socioeconomic indicators set the stage for developing effective intervention models and operative policy for diabetes adherence in countries facing loss of earning power due to the epidemic.

GUIDELINES FOR DIABETES CARE IN THE CARIBBEAN

Cunningham-Myrie and colleagues (2008) suggested that in health care environments with these deficiencies in health information reporting and quality management, diabetes adherence requires a unique approach. In response to the growth of the epidemic, the Caribbean Health Research Council (CHRC), whose mission is to promote best practices in health and policy based on available evidence, in collaboration with the Pan American Health Organization (PAHO), met in 2006 to generate a manual for a more effective and comprehensive approach to diabetes mellitus management and prevention. The manual, *Managing Diabetes in Primary Care in the Caribbean*, was aimed at the cultural and economic aspects of Caribbean health care systems (PAHO & CHRC, 2006). The guidelines described are similar to those set by the International Diabetes Federation in collaboration with the World Health Organization, with the exception of goals for low-density lipoprotein cholesterol (Boyne, 2009). These distinctions in criteria for screening, diabetes diagnosis, treatment, and care guidelines are outlined more specifically in Appendix Table 1 and are compared to the guidelines set by the American Diabetes Association. Fasting Plasma Glucose is the most widely utilized diagnostic tool for the Caribbean at present, and oral glucose-lowering agents, Metformin, or insulin treatment are generally recommended once a diagnosis is confirmed (PAHO & CHRC, 2006). However, limited information is circulated on availability and accessibility of these treatments.

Fortunately, the CHRC guidelines also recommend non-pharmacological treatment, such as individualized Self-Monitoring Blood Glucose (SMBG) plans, medical nutrition treatment, and physical activity management. These types of interventions may delay or reduce the need for pharmaceuticals, which may not always be in supply. They also have been recommended for the Caribbean due to increased prevalence of fast food venues and decreased critical nutrients, such as calcium, zinc, and fiber. A study in Barbados that evaluated food diaries of 49 adults found that sugar intake was four times the recommended amount, making up a larger proportion of available energy compared to five years prior (Sharma et al., 2008). The Caribbean Food and Nutrition Institute issued a manual on nutritional management of diabetes, but efforts toward nutritional initiatives are hindered by lack of trained personnel such as dieticians (PAHO & CFNI 2004; Adams & Carter, 2011b). With the help of PAHO and the Food and Agriculture Organization, Food-Based Dietary Guidelines were established for the Eastern Caribbean to promote healthy diets and eating behavior. Although it had initial support of multiple countries and organizations, that support eventually dwindled and failed to reduce the price of food or availability of healthy food for the consumer (Albert et al., 2007).

The history of landmark events in NCD control for the Caribbean begins in 1986, when the Caribbean Cooperation in Health Initiative recognized NCD as a priority area. In 2005, Dr. George Alleyne submitted the Report of the Caribbean Commission on Health and Development for the 26th Meeting of the CARICOM Heads of Government in St. Lucia. This report documented the health and economic burden of hypertension and diabetes in the region and thus NCDs were named a super priority. Other such events are outlined in Table 2.

Notable successes include events such as Caribbean Wellness Day, practiced in 19 Caribbean nations today, as well as the Health Caribbean Coalition, and the Framework Convention on Tobacco Control ratification (Hospedales et al., 2011). While none deal specifically with diabetes, these events are evidence of community advocacy and subsequent government support to draw attention to NCD.

Table 2. Landmark Events in Prevention and Control of Chronic Non-communicable Diseases in the Caribbean Community, 1986-2011

1.	Caribbean Cooperation in Health Initiative approved by ministers of health in 1986: (1995-2003, 2005-2009, 2010-2015) includes NCDs as a priority area.
2.	CARICOM* Heads of Government, 2001 Nassau Declaration, "The Wealth of the Region is the Health of the Region" gave direction to a regional approach to NCDs.
3.	Caribbean Commission on Health and Development, 2005, names NCDs a super priority.
4.	CARICOM Heads of Government Summit on NCDs, 2007, issues the NCD Summit Declaration "Uniting to Stop the Epidemic of Chronic NCDs."

Note: *Caribbean Community

Source: Hospedales et al., 2011

PART 2
Barriers Contributing to Diabetes Treatment Non-Adherence

FRAMEWORKS TO ADDRESS BARRIERS TO ADHERENCE AND METHODS OF STUDY

Of 84 articles originally reviewed, 64 were included in this study. A flowchart of research activity for the present study is shown in Appendix Figure 1. Articles published in English and in 2004 or later were included in this study. Primary contributing journals include the *West Indian Medical Journal, Diabetes Care, Diabetic Medicine, Quality in Primary Care,* and *Primary Care Diabetes*, as well as articles published by the WHO, PAHO, or the CHRC. A research matrix of all articles included in this study is available in Appendix Table 2, detailing subjects, publication years, authors, sources, purpose of study, and brief conclusions of the studies.

A WHO publication on adherence to long-term therapies used Barofsky's (1978) definition of diabetes adherence, which is "conceptualized as the active, voluntary involvement of the patient in the management of his or her disease, by following a mutually agreed course of treatment and sharing responsibility between the patient and the health care providers." Diabetes is unique, even for a chronic disease. Adherence to treatment cannot be measured by a single construct since the regimen has multiple strategies to improve long-term glucose control, including self-monitoring of blood glucose, insulin injection or oral agents, diet, physical activity, foot care, and other self-care measures (WHO, 2003a). To complicate matters, the WHO document adds that elements of the disease itself provoke non-adherence, such as treatment complexity, duration of disease prior to treatment, and delivery of care.

Adherence to medication was measured in a large cross-national study in 2005 by the International DAWN (Diabetes Attitudes, Wishes, and Needs) Advisory Panel, which included adult patients with Type 1 or Type 2 diabetes (n=5,104) as well as physicians and nursing staff (n=3,827). Thirteen mostly developed countries were selected for study, representing Asia, Australia, Europe, and North America. Outcome measures included patient and provider reports of successful adherence based on five domains: diet, exercise, medication, self-monitoring, and appointment keeping. According to patients, adherence did not vary significantly by type of diabetes; however, according to providers, adherence for Type 1 diabetics was significantly higher compared to Type 2 diabetics for all domains. They reported that 46% of Type 1 and 39% of Type 2 patients achieved adherence for at least two-thirds of these domains, with significantly lower adherence for lifestyle domains compared to other self-care mechanisms. Such countries as Germany, the Netherlands, and the United Kingdom reported higher percentage adherence compared to such countries as India, United States, and Scandinavian nations, although adherence across all countries was less than ideal (Peyrot et al., 2005).

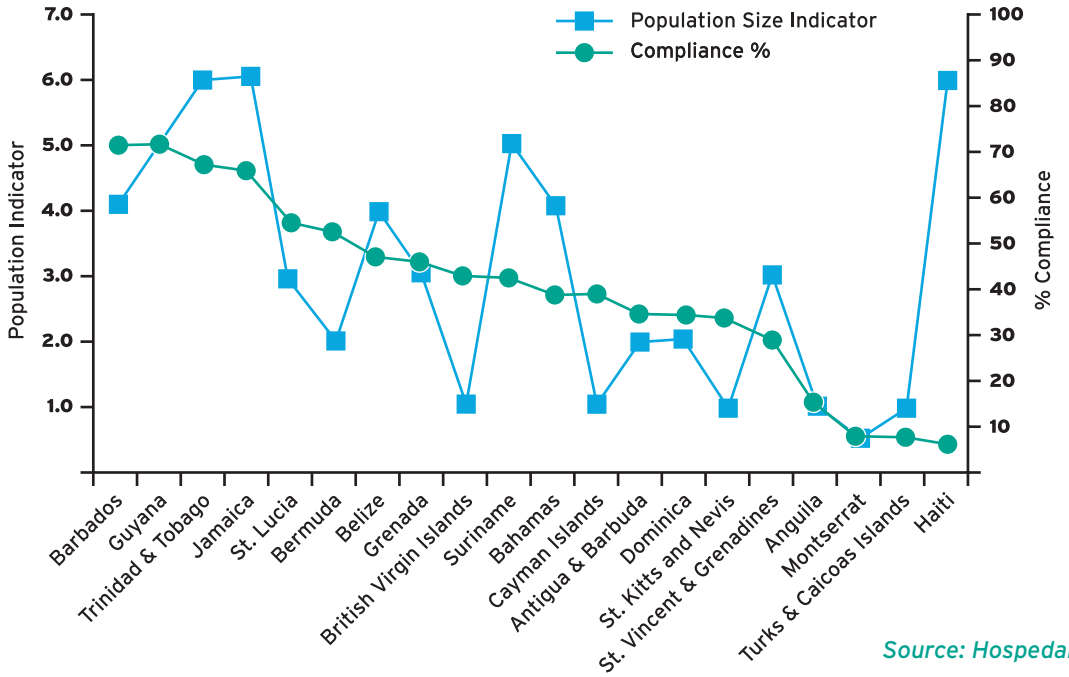
Even in the United Kingdom where adherence is relatively high, one study in collaboration with the London School of Medicine and Dentistry showed that poor adherence to diabetes regimens for those with Type 2 diabetes affects one out of 10 people. The team synthesized open-ended reviews from 128 diabetic patients and assembled a series of reasons for non-compliance, which include issues with therapy, poor patient knowledge, psychosocial or mental health issues, and occupational factors. Side effects of therapy, defined as limitations due to adverse effects, was reported by 16.4% of participants and contributed to non-adherence. A dietitian assessed the degree of concordance with lifestyle changes, another major barrier (26.5%). Non-attendance was reported for 16.4% of participants and meant the patient had missed more than 30% of their scheduled appointments (Khan, Lasker & Chowdhury, 2011). Non-adherence even plagues the health systems that have provisions and commodities necessary to prevent and treat diabetes.

Adherence rates for NCDs in the Caribbean were divulged at the first CARICOM heads of government, multisectoral summit in Port-of-Spain in 2007, dedicated to NCD evaluation in the Caribbean. Figure 2 shows reports of compliance from each country present at the Summit, where in, St. Lucia leads

the Eastern Caribbean with highest adherence of about 50 percent, and St. Vincent & Grenadines lags behind with about 30 percent adherence. While this is not diabetes-specific, it represents the overall low adherence rates for chronic disease.

In order to effectively focus interventions that target the right problems, those problems must first be identified and categorized. The 2003 WHO publication and the work of Peter Adams and Anne Carter in Barbados, both utilize a barrier classification model that helps conceptualize the coupled underlying barrier categories: *provider/health system*-level, and *patient/society*-level. The WHO document suggests that provider-level barriers have to do with the quality of the relationship between the patient and provider, as well as available social support from the medical community. Provider-level barriers often arise due to the health system structure, whose own barriers may include problems like supply shortages. Meanwhile patient-level barriers refer to those experienced in self-care adherence, such as cost, perceived self-efficacy, or stress. Society-level barriers are often the cause of patient-level barriers by providing a social basis for decision-making. Society-level barriers, for instance, are high-risk situations, such as political turmoil, or simply environmental systems, such as economic recession (WHO, 2003a). In Adams and Carter's focus group meetings, providers (2010 study) and diabetic patients (2011a study) divulged many Caribbean-specific reasons for non-adherence. This framework will be used to identify and categorize barriers to diabetes medication/therapy adherence specific to the Caribbean, all of which are synthesized into a diagram in Figure 3 and explored in the next part of this meta-analysis.

Figure 2. CARICOM countries' percent compliance with non-communicable disease Summit Declaration versus population indicator, 2010.



Source: Hospedales et al., 2011

HEALTH SYSTEM AND PROVIDER BARRIERS TO EFFECTIVE DIABETES CARE

Often provider-level barriers to treatment adherence or effective prevention techniques are intertwined with failures of the health system in general, and appropriate interventions will target those two birds with the same stone. For example, "failure to fully examine" is a provider-level barrier; however, it may be due to the fact that the doctor-to-patient ratio is low (a health system level barrier), so the doctor must prioritize his or her time strategically. Therefore, we must address the two types of barriers in conjunction with each other.

In the Adams and Carter 2010 study, 63 individuals were involved in 13 focus group discussions, including physicians, nurses, pharmacists, podiatrists, and dieticians. These provider participants were asked about their own adherence to CHRC diabetes guidelines, as well as reasons patients do not adhere. Practitioners suggested the guidelines were "outdated, not patient centered, difficult to remember, and did not give advice on how to tackle barriers" and were more likely to follow the WHO or American Diabetes Association guidelines, which are "available online, updated regularly and promoted at conferences." (Adams & Carter, 2010;3) Providers also remarked that copies of the guidelines were not shared with non-physicians, thereby restricting the clinical interface to physician-only encounters. Moreover, there was no copy of the guidelines available for patients themselves, which would put them in a better position to manage and monitor their individual case and become more participatory in the intervention process. Private practitioners tend to follow the WHO or American Diabetes Association guidelines, whereas public or polyclinic physicians were more likely to utilize local resources, leading to inequities in patient outcomes between the two sectors (Adams & Carter, 2010). These inconsistencies are partially responsible for non-adherence to treatment in the Caribbean.

Provider-level barriers that were mentioned included an uncoordinated team care approach, where different health professionals give contradictory information, thereby confusing the patient and leading to non-adherence. Miscommunication or failure to communicate also leads to non-adherence. Patients spend more time with the non-physician on a typical visit, and are more likely to divulge non-adherence to them, which is then not communicated to the physician. However, providers in the focus groups felt the quality of care was high (Adams & Carter, 2010). Corroborating these results on fragmented care, the DAWN study found that providers generally attribute patient non-adherence to psychological problems, such as diabetes-related distress and psychological well-being, yet providers themselves are not able to manage those problems and provide the necessary care to affected patients. Additionally, although providers consider psychological problems to be an obstruction to care, few patients are referred for psychological services. The study suggests that interventions include models of care that integrate psychosocial and mental health services, and models that train providers to more confidently recognize psychological interference with care (Peyrot et al., 2005). While this is a failure at the provider level to appropriately control patient complaints, it is also a reflection of disconnected health systems.

In Barbados, the Adams and Carter focus groups also identified systemic gaps that amount to barriers to adherence for diabetics boil down to three predominant supply issues: medical supply, educational supply, and human resources. Providers identified a need for equipment such as hemoglobin A1c reagents, blood pressure cuffs, educational videos, and blood tubes, mostly in polyclinic (public) facilities in Barbados. Due to limited supply, diabetic patients are often not given their full month's dosage of medication. This medication rationing is confusing to patients, directly and indirectly leads to non-adherence, and occurs mostly in polyclinic pharmacies. Lack of educated health professionals, such as dieticians, to deal with patient flow also leads to longer waiting periods and inadequate patient-provider interactions.

Adams and Carter's follow-up study in 2011 evaluated responses from five focus groups, two groups of Type 2 diabetics, two groups with hypertension, and one with both. All were over 40 years of age and were recruited by telephone

if they responded positively for having diabetes or hypertension. Participants discussed provider-level barriers, alluding to practitioners who treat the disease instead of the "whole person" —a sentiment echoed in multiple studies on the subject of patient-provider interaction. The idea of the "whole person" stresses the consideration of patient ideas, concerns and expectations and takes a person-focused approach as opposed to the physician-focused, biomedical approach. Knowledge of the patient's attitudes and this "whole person" approach is associated with patient compliance (Safran et al., 1998). Other provider-level barriers included failure to communicate with other health professionals resulting in disruption of the continuity of care, failure to fully examine the individual or withholding pertinent information. They additionally discussed barriers related to the system, including the elevated cost of drugs, medication supply, and long wait periods at clinics (Adams & Carter, 2011a).

The same team published an additional study in 2011 by auditing charts of diabetic patients to determine whether or not guidelines were met for diabetes care. At this point in Barbados, more than 19% of the population over 40 years old was considered diabetic. Researchers found provider-level discrepancies between private and polyclinic protocol. Public providers were more likely to report a patient's weight, foot examination, total cholesterol, serum creatinine, urine albumin, history/advice given on lifestyle habits, and offer diet advice or referral to a dietician. Private patients were exposed to fewer of these exams, but more fasting, blood, glucose (FBG) tests than public patients. They also discovered that most of the general methods used in diabetes care needed improvement, including "body mass assessment, lifestyle advice, screening for retinopathy, monitoring blood glucose control, and achieving BP and glycaemic targets." However, although the clinical protocol varied between facilities, clinical targets were similar for both private and public practices with the exception of better results for private practices on HbA1c targets (Adams & Carter, 2011b).

A comparable study was done in Trinidad using the CHRC guidelines for comparison. Similar to the Barbados study, researchers identified gaps in management and care that did not meet the standards of the 2006 CHRC. In the study sample, neither body mass index (BMI) nor waist circumference were ever measured at any visit, FPG was measured in 97.2% of patients on their first visit, and educational status was only recorded for 0.3% of patients. At follow-up visits, 8.5% of patients received foot inspections, 0.3% were advised on self-monitoring blood glucose (SMBG), 34.2% were advised about dieting, 18.5% were advised on exercise, and 47.2% spoke with their provider about compliance with treatment. Researchers speculate that failure to meet these guidelines is due to the burdened healthcare system, specifically the poor doctor-patient ratio. Researchers also suspect that some health indicators are actually completed, but never recorded, emphasizing the need for continuing education for staff and effective information reporting systems (Pinto Pereira et al., 2009). These findings were corroborated by another Trinidad study (Morren, Baboolal, Davis & McRae, 2010).

INDIVIDUAL PATIENT AND SOCIETAL BARRIERS TO EFFECTIVE DIABETES CARE

Patient-level barriers and societal barriers can also be addressed in union because they are also inextricably linked. For example, in a culture that prides itself on its work ethic, individuals may feel societal pressure to choose work over their own health, resulting in non-attendance at doctor's appointments, worsening conditions, and overall anxiety. This section will address the individual barriers, which are often based on social constructs, specific to diabetes adherence in the Caribbean.

Denial of disease arose as a potential barrier to patients among Adams and Carter's provider focus groups. Inadvertent non-adherence, such as confusion about the regimen, as well as lack of understanding or forgetfulness due to additional regimens for co-morbidities, were also mentioned. Both financial and time costs to the individual were cited as other reasons for non-adherence. Fear of needles, as well as side effects of medication such as fatigue and impotence, also contributed (Adams & Carter, 2010). A study from Trinidad corroborates these findings, saying that 15.7% of Type 2

diabetics in the study consider fear of needles a barrier to adherence, adding that acquiring test strips was problematic for 49.4% of Type 2 diabetics (Ezenwaka et al., 2012). Reluctance towards behavior change involved with diabetes care was also mentioned as a barrier to adherence (Adams & Carter, 2010). The patient-led focus groups additionally confessed that dietary and lifestyle changes were a difficult part of adherence in managing diabetes (Adams & Carter, 2011a). Forty years of eating and exercise habits are difficult to amend.

Practitioners also mentioned Barbadian cultural factors that they believe patients face that lead to non-adherence, such as difficulty obtaining time off from work for health reasons due to work stress, which was also mentioned in the patient-led focus groups from the 2011 study. Other societal and cultural barriers mentioned include: Barbadian footwear, diet high in salt and fat, negative attitudes toward western medicine and exercise, cultural acceptance of obesity, general lack of social support for those with diabetes, and overreaction to potential side effects. A separate study in Haiti suggested that food-related beliefs may impede effective nutritional therapy (Wiese, 1976). The patient-led focus groups agreed that there was a lack of social support, and also cited being stigmatized in society despite their acceptable body weight. Unlike the provider-led focus groups, the patient-led groups mentioned inflated prices of food, and the prevalence and accessibility of unhealthy food as barriers to self-care. Healthy food is costly, posing a larger threat to low-income diabetes patients than non-diabetics. While none of the participants had seen guidelines for diabetes care, they were all interested in having a copy for themselves (Adams & Carter, 2011a).

Culture-driven religious beliefs prohibiting use of treatment or promoting use of alternative treatment were identified as barriers in multiple studies, including that of Moss and McDowell, who in their study of a rural Vincentian community found that non-prescription medication was viewed as effective, and God was viewed as the source of treatment information (Moss & McDowell, 2005). This finding was corroborated by Smith in a cultural consensus beliefs study of Afro-Caribbean women living in Florida in 2011. A questionnaire was distributed to 30 women to investigate patient-level influences on self-management of Type 2 diabetes. The study, done by convenience sampling and informant interviews, showed that these women did share a single cultural belief model, despite being from mostly Trinidad and Tobago or Jamaica. Main themes emerging from the interviews included persistence of use of traditional Caribbean medicines, such as caerasse, melon, cinnamon bark, mauby bark, aloe, bush tea, and celery. Fifty-seven percent of women reported use of these treatments for their diabetes. They believed their prescribed medicines were complementary, and that the traditional regimens would decrease their reliance on the prescriptions. Seventy-six percent of the women believed their Caribbean lifestyle and diet was not conducive to glucose control, and only 10% of participants mentioned physical activity as a means of controlling their diabetes. Another common theme in the interviews was prayer and faith. Ninety percent of participants saw prayer as a complementary method of treatment. These findings contribute to our understanding of the problem of adherence in participant's home countries in the Caribbean even though no similar studies of that nature have been conducted (Smith, 2011).

These studies have answered many critical questions about diabetes adherence models around the globe and in the Caribbean. Youth, mentioned earlier as a vulnerable segment of the population suffering from Type 1 and increasing obesity, cardiovascular disease, and risk of Type 2 onset, have high non-compliance rates compared to other age groups, thus presenting a need for more thorough interventions targeting young people with elevated risk (Pinto Pereira et al., 2009). Additionally, those with complications of diabetes suffer more complex barriers to adherence, which deserve further investigation (Vilela de Castro & Mesquita, 2009; Balkaran et al., 2011). Figure 3 is a diagram depicting the barriers mentioned in this section. Using the Adams and Carter framework of four domains that affect patient adherence (patient, provider, health system, and society), academics, programmers, and health policy planners can more easily tackle barriers and begin to design effective intervention campaigns, which is the focus of the following section.

Figure 3. Patient, provider, health system, and societal barriers to diabetes medication adherence in the Caribbean.

Patient	Society	Health System	Delivery of Care (1,2,3)
Age/Gender (1)	High Risk Situations (1)	Guidelines not well distributed, lack enforcement, and not applicable (2,3,8,12)	Social Support from Medical Community (1,2)
Depression/Stress (1, 7)	Social Situation (Housing, Employment) (1,5)	Wait Times (3)	Inability to manage psychological well-being (7)
Alcohol Use & Diet (1,2)	Religious/cultural Paradigm (9,10,11)	Medication & Supply Shortages (1,2,3)	Abandonment of Guidelines (2,4)
Treatment complexity (1)	Work Stress (2,3,5)	Human Resource Shortages (2,3)	Physician-focused, Biomedical Approach (3)
Duration of Disease (1)	Acceptance of Obesity and Diet High in Salt/Fat (2)	Discrepancies between Public & Private Care (3)	Medication Rationing (2)
Inadvertent Non-adherence (1,2,5)	Negative Attitudes toward Physical Activity (2)	Lack of Continuity of Care (1,2,3)	Physician-only Training (2)
Cost (1,2,6)	Reliance on Alternative Therapy (2)	Limited CME and Health Education & Promotion for Diabetes (2,3)	Doctor-Patient Ratio (4)
Non-Attendance for appointment (2,3,5)	Lack of Social Support & Stigma (2,3)		Poor Interdepartmental Communication (2,3)
Fear of Side Effects/Needles (2,5,6)	Inavailability of Healthy Food (3)		
Compliance with Lifestyle changes (2,3,5)	Inflated Food Prices (3)		
Reluctance toward Behavior Change (2)			
Perceived Self-Efficacy (1)			
Denial (2,5)			
Mental Health Concerns (5)			

Sources: (1) WHO, 2003a not Caribbean-specific; (2) Adams & Carter, 2010; (3) Adams & Carter, 2011a; (4) Pinto Pereira et al., 2009; (5) Khan, Lasker & Chowdhury, 2011; (6) Ezenwaka et al., 2012; (7) Peyrot et al., 2005; (8) PAHO, CFNI, 2004; (9) Moss & McDowell, 2005; (10) Smith, 2011;

PART 3
International and Caribbean-Specific Intervention Models to Support Diabetes Treatment Adherence

The success of interventions at the macro, health system-level compared to those at the micro, patient-level depend entirely on settings and resources available. In a study from Trinidad, for example, macro-level interventions such as health sector reform were found to have more impact than micro-level interventions, such as targeted clinical practice guidelines or educational interventions (Mahabir & Gulliford, 2005). Interventions to improve diabetes care around the world are designed based on potential opportunities at both the system and patient level for minimizing risk factors and improving health outcomes; current evidence-based studies include concepts of technological, behavioral, pharmacist-led, and health system-level interventions. These interventions are cross-referenced with the previous framework in Table 3. All interventions mentioned here give some indication of success in their original study environment, by targeting one or more of the barriers discussed in the previous section to improve glycemic control.

TECHNOLOGICAL INTERVENTIONS FOR IMPROVING COMPLIANCE

Technological interventions at the health system-level have been accepted as part of comprehensive care around the world for diabetes management. Receiving mixed reviews, many intervention studies yield insignificant biophysical change for the participants (Del Prato et al., 2012; Rodriguez-Idigoras et al., 2009). Peer versus diabetes specialist nurse automated telephone calls was the intervention of interest in a study in the United Kingdom. Although there was no significant clinical outcome, 94% of participants in the group receiving calls from diabetes specialist nurses reported that they would recommend the program to others. The calls were a useful addition to diabetes management, and recently diagnosed patients benefitted more than those in adequate control of their illness (Dale, Caramlau, Sturt, Friede & Walker, 2009). Piette (2007) suggests that interactive behavior change technology, including personal digital assistants, automated telephone calls, Web sites, and touch screen kiosks have health benefits. Additionally, a 2012 review of diabetes telecare literature yielded highest significance for studies that used telemedicine to enhance behavioral therapy (Siriwardena et al., 2012). Another highly successful program, u-healthcare, was evaluated in South Korea in 2011 by Lim and colleagues. Over six months, 144 patients were randomly assigned routine care, SMBG, or u-healthcare. U-healthcare offers clinical support through mobile phones with built-in glucometers, and this intervention resulted in decreased glucose, weight, BMI, and LDL cholesterol (Lim et al., 2011).

Telecare interventions may be less effective upon implementation in the Eastern Caribbean. Although mobile phone use is rapidly increasing (Sutherland, 2010), not everyone in the Eastern Caribbean has access to telephones, making telecare interventions less effective than they were in the Dale and colleagues study. Theoretically, only people with cellular phones in regions near cell towers, and willing to use their cellular phone minutes for telecare, would sign up and receive care. On top of issues of equitability, another complexity of this technological intervention is the training of the already burdened and limited staff to implement and use it. Training staff to use technology is a complexity familiar to all forms of technological interventions and would be difficult to implement across the Eastern Caribbean where commodities such as internet use range from 32.2% in Grenada to 88.5% in St. Lucia (Table 1). However, despite these barriers, one country in the Eastern Caribbean has implemented a telemedicine system as a means of improving physician-specialist communications. Tapion Hospital in St. Lucia works with a partner in Miami, Florida in the field of teleradiology, and has been utilizing telemedicine as a tool for distance learning to improve service delivery (Health Systems 20/20 & SHOPS, 2012d).

BEHAVIORAL AND PEER-LED INTERVENTIONS TO IMPROVING COMPLIANCE

Behavioral and peer-led interventions surfaced in response to the need to address the psychological and environmental barriers in dealing with chronic disease, particularly among youth, who are most strongly influenced by the activities of their peers and immediate surroundings. A family-focused intervention in the U.S. tried to address Type 1 diabetes treatment adherence for adolescents. Families in one branch of the intervention were given 10 sessions of behavioral-family systems therapy (BFST), another branch was given education and support therapy, and a third was given current therapy (n=119). Evaluations were done six months and 12 months after initiation, and results were mixed. The study succeeded in improving parent-adolescent relationships and long-term treatment adherence, but did not change immediate diabetes control for adolescents with Type 1 diabetes. Researchers concluded that variations of BFST could increase its impact on families dealing with youth who have diabetes (Wysocki, Greco, Harris, Bubb & White, 2001).

Expanding on this family-focused intervention, a separate team in Boston is currently working on Personally Controlled Health Records (PCHR) for improving chronic Type 1 diabetes care among youth. Based on elements of the Chronic Care Model[1], timely flow of information, and individualized services, as well as multiple-stakeholder support (clinical care team, peers, parents, engaged patient), the PCHR model offers high flexibility to the empowered patient in "real-time." While issues of privacy and evaluations have yet to be addressed, engaging youth from this PCHR platform promises to serve the needs of this high-risk group, and to achieve the national objective of strengthening health systems monitoring technology (Weitzman, Kaci, Quinn & Mandl, 2011).

Another behavioral intervention in Michigan trained laypeople to be Peer Lifestyle Coaches (PLC), promoting self-management strategies and behavior change skills in an African Methodist Episcopal church-based diabetes intervention program. This customized intervention resulted in high participation, retention, acceptability, and satisfaction on the part of the PLCs (Tang, Nwankwo, Whiten & Oney, 2012). No anthropometric measures were taken; however, using lay persons instead of health care professionals as part of a church-based initiative helped tailor the program to meet the needs of these specific participants—a technique that can be easily replicated in the Caribbean due to the high value placed on religious fellowship.

One attempt at addressing behavior change was tried in Trinidad in 2011. Sixty-two Type 2 diabetic patients per intervention arm were recruited from a single clinic. The intervention consisted of identifying each patient's position within the Stages of Change model for chronic disease, and using personalized care during patient-provider consultations for a 48-week period. The Stages of Change model uses five steps toward behavior change: precontemplation, contemplation, preparation, action, and maintenance. Researchers used HbA1c and patients' readiness to change, which was measured by identification of stage for diet, exercise, and medication management. Over time, glycemic control actually worsened for the intervention group, while dietary and exercise behavior shifted to a more positive stage, and medication use showed little change. Limitations are said to be due to economic hardship and lack of blinding capability (Partapsingh, Maharaj & Rawlins, 2011).

Variations on family-based intervention therapy seems the most viable option to begin focusing on youth onset in the Eastern Caribbean; however, lack of basic infrastructure required for these programs may be problematic (Tulloch-Reid & Walker, 2009). Behavioral interventions require high commitment on the part of multiple stakeholders, at the health system, community, and individual levels. If successful, empowering and engaging people by issuing them a copy of their records and providing them with an educational support network could help address not only Type 1, but Type 2 diabetics in the Caribbean.

[1] Elements of the Chronic Care Model include self-management support, decision support, organization of care, community linkages, delivery system design, and clinical information systems (Wagner et al., 2001) searched primarily using PubMed, publication date from 2005 to recent.

PHARMACIST-LED INTERVENTIONS FOR IMPROVING COMPLIANCE

A provider-level intervention study in the greater Seattle, WA area of the United States involved the training of pharmacists to lead in the development of individualized diabetes plans and establish regular communication with their Type 2 diabetic patients (*n*=77). Designed as a randomized control trial, outcomes for the study were medication appropriateness, self-reported adherence, and HbA1c, and they were measured at baseline, six months, and 12 months. However, none of these measures significantly improved, according to the study. One benefit of the study was that participants relied more on trained pharmacists than on physician-visits, thereby decreasing the burden at physician's clinics (Odegard, Goo, Hummel, Williams & Gray, 2005). Shifting the burden in this way could be one strategy to improve health system efficiency.

Using a quasi-experimental study design in 2009, Rivera-Sarate and colleagues evaluated another pharmacist-led initiative in Puerto Rico, similar to the Odegard et al. 2005 study. They took a sample of 250 participants using community pharmacies in Puerto Rico where the SIMPLE program was implemented and measured outcomes of consumer knowledge, compliance, and satisfaction. SIMPLE stands for **S**epa **I**nformacion correcta sobre **M**edicinas, **P**regunte, **L**ea la etiqueta y **E**vite problemas (know correct information about medicines, ask, read the label, and avoid problems), and while SIMPLE does not address diabetes in particular, it provides a framework for a system that could work in a Caribbean environment for patients with chronic disease. Making the process highly inter-personal, pharmacists had six encounters with patients where they discussed correct medication use, evaluated the patient's medical history, developed a plan for medication use, and evaluated compliance and errors. Admittedly, it was difficult to change the way pharmacy is practiced and perceived in Puerto Rico, but the intervention resulted in increased knowledge of and compliance with the prescribed medications. An added benefit of the program was enhanced participant-pharmacist relationships (Rivera-Sarate, Gonzalez-Cordero, Gutierrez-Collazo & Rios-Motta, 2009).

As discussed previously, non-compliance in the Caribbean region is caused by several health system-level factors, including poor doctor-to-patient ratios, staff vacancies, and wait times. Educating all parties about increasing use of pharmacists as a resource, diabetic patients may make fewer office visits and more visits to the pharmacy, thereby easing the burden on primary care clinics. When non-physician staff members, such as pharmacists, are utilized to their potential, non-compliance could be minimized.

HEALTH SYSTEM INTERVENTIONS FOR IMPROVING COMPLIANCE

Working through PAHO, the Mexican government, and Johns Hopkins School of Public Health, collaborative learning techniques to improve diabetes outcomes were studied for 10 health clinics in Mexico in 2010. They randomized the system-level intervention: five health centers received standard of care, and five received Breakthrough Series (BTS) methodology, an intervention used in more than 50 health systems around the world and developed by the Institute for Health Improvement in Boston (Wagner et al., 2001). For the Mexican study, a collaborative approach coupled BTS methodology with elements of the Chronic Care Model and amounted to three learning sessions targeting "self-management support, decision support, delivery system design, and clinical information systems." Over 18 months, the intervention succeeded in improving glycemic control and quality improvement measures, and incorporation of the medical team was regarded as essential to improvement. Although this study showed significant improvements in anthropometric measures, it was impossible to determine whether these significant improvements can be attributed to increased compliance (not recorded in study) or other factors, such as pre-existing significant differences between groups (Barcelo et al., 2010).

Another recent study of a chronic disease clinic in Trinidad selected 101 volunteers to partake in *DiaC*, a three-year program that included longer consultation times, more appointments, and lifestyle advice than patients at the chronic disease clinic. The measures were limited to HbA1c analysis at baseline, three, 24, and 36 months after program implementation. Readings staggered over time, starting from 9.44 at baseline, and reaching 7.96 after 36 months. It should also be noted that significant drops in HbA1c did not occur until the 24-month period, and no drops were seen until after three months at least. Researchers were impressed with the outcomes, and determined that these low-cost clinics where special focus is given to diabetes patients in a primary care setting could be established across the developing world (Babwah, 2011).

In 2008, Bobb and colleagues at the University of the West Indies evaluated another Trinidad success story. A government medication coverage plan was initiated in 2003 to make the cost of drugs cheaper for diabetes patients: a health system-level intervention. Trinidad has a Type 2 diabetes prevalence of 20%, and patients can access care and treatment through private insurance schemes or free from the public health care system. However, the public system is burdened and prescriptions were not often filled optimally. Outcome measures for the program, called CDAP (Chronic Disease Assistance Plan), included: attitudes of patients and pharmacists, and measurements of glycemic control for Type 2 diabetics receiving program-only drugs. Over a six-month period, researchers found that out of 208 participants, 61.5% exhibited good glycemic control and 94% were satisfied with the CDAP program. A central limitation of this study is medication supply—also one of the barriers mentioned earlier in the current analysis. Seventy-three percent of respondents believe this is an impediment to the CDAP program. Treatment is also limited to the types of medications provided by the program through the Ministry of Health, which strictly include the sulphonylureas, metformin, and insulin (Bobb et al., 2008). The CDAP program has more recently been expanded to include provision of free blood glucose meters and testing strips, which are accessible with their new national "smart card" called MY TT CARD, and has yet to be evaluated for effectiveness (Ministry of Health, 2012).

The Barcelo study shows that the BTS model coupled with the Chronic Care Model can be effective in low-resource settings, a quality shared with the Eastern Caribbean. While BTS seems viable, it requires immense human and material resources to train patients and primary care personnel. This kind of intervention would require the unwavering support of health ministries and many other agencies. However, Trinidad and Tobago has managed to work around those barriers and garner a series of effective solutions for their diabetes epidemic with the help of health system-level changes.

While systemic modifications are highly effective for guiding behavior change, poor adherence can be most effective by using a multipronged approach, involving interventions that address every possible level of care (patient/societal, provider/system) (Wagner et al., 2001). Table 3 reviews options and opportunities for the Caribbean nations to expand their reach in dealing with non-compliance to Diabetes medication based on mentioned studies. Some studies in low-income, low-resource nations can provide interesting lessons toward compliance in the Eastern Caribbean, and they will provide a context for suggestions for future campaigns.

Table 3. Suggestive Interventions for Improving Adherence to Therapy for the Control of Diabetes in the Eastern Caribbean, by Author and Modification Target Level

Author, Year	Intervention	Target Level*
Caribbean		
Health Systems 20/20 & SHOPS, 2012	Telemedicine/Teleradiology	Individual, Provider, Health System
Partapsingh, Maharaj & Rawlins, 2011	Stages of change personalized care	Individual, Provider, Health System
Babwah, 2011	DiaC Diabetes specialized clinics	Individual, Provider, Health System
Non-Caribbean		
Dale et al., 2009	Automated calls from DSNs** and peers	Individual, Provider, Health System
Piette et al., 2007	Interactive Behavior Change Technology	Individual, Provider, Health System, Society
Lim et al., 2011	U-Healthcare mobile phones	Individual, Provider, Health System, Society
Wysocki et al., 2001	Behavioral Family Systems Therapy	Individual, Health System, Society
Weitzman et al., 2011	Personally Controlled Health Records/CCM	Individual, Provider, Health System, Society
Tang et al., 2012	Church-based Peer Lifestyle Coach	Individual, Society
Odegard et al. 2005; Rivera-Sarate et al., 2009	Pharmacist-led	Individual, Provider, Health System, Society
Wagner et al. 2001; Barcelo et al., 2010	Breakthrough Series Methodology/CCM	Individual, Provider, Health System, Society

Notes: **I=individual/patient level* (involved patient education/assessment), *P=provider level* (target provider), *HS=health system level* (alter how environmental determinants influence self-management behavior), *S=Society level* (involve mobilizing society or community preparedness)
** Diabetes Specialist Nurse

PART 4
Caribbean-Specific Recommendations for Interventional Support of Diabetes Treatment Adherence

The patient-led focus groups in Barbados subjectively discussed several recommendations for how to proceed with diabetes care and glucose maintenance. They suggest promoting self-regulatory behavior, such as practicing moderation and allowing occasional indulgences. Practitioners, they determined, should embrace a more patient-centered approach by trying to empathize with those undergoing difficult lifestyle changes. Provision of diabetes-related information was also requested. At the health system level, participants wanted improved continuity of care that prioritized them, as well as their own patient version of the CHRC guidelines for care. They also recommended societal changes, such as lowering the price of healthy food, better access to fitness facilities that would supervise diabetes-specific programs, increased support groups, and education of the general public about diabetes (Adams & Carter, 2011a). The provider-led focus groups also believed that educational campaigns similar to those applied to AIDS programs in Barbados would be most effective. These educational campaigns must contain patient-centered messages urging the incorporation of healthy foods and exercise into their lifestyle, messages about patient responsibility and self-monitoring, and messages concerning denial and stigma (Adams & Carter, 2010).

An idea that arose in multiple discussions was the notion of a "diabetes and hypertension passport," which includes guidelines for care and diabetes promotional/educational information, as well as their own individualized improvement plan they could take to each provider they see. This type of patient-centered, individualized care plan serves to empower patients, and makes them responsible for their own health status. In general, it was agreed upon that the patient passport containing patient records and diabetes information would be an effective intervention contributing to better health outcomes for patients with diabetes (Adams & Carter, 2010; Adams & Carter, 2011a). Provider participants also suggested screening programs in public domains, as well as provision of free home self-monitor devices for those who attend educational workshops. Case conferences, redistribution of office space, and task sharing were discussed as a means of involving all caretakers and applying a team approach. It was also suggested that physicians be required to participate in continuing medical education for chronic disease management, as none is currently required (Adams & Carter, 2010). Task sharing was also suggested in the Pinto Pereira study in Trinidad so that non-physician staff can record indicators such as BMI and waist circumference indicators, not currently well measured but required by the CHRC guidelines (Pinto Pereira et al., 2009).

These studies provided valuable insight into both potential barriers and potential solutions to improving diabetes control in the Eastern Caribbean. However, we cannot know for sure until steady monitoring and evaluative activities are begun. The STEPWise approach to NCD surveillance was developed by WHO to establish a standardized data collection method, which can be tailored to specific community concerns. The steps and aspects of disease are shown in Table 4 and include a responsive timeframe for collecting questionnaire data, physical measurements, and biochemical measurements. According to the 2012 USAID Health Systems 20/20 report, Dominica successfully implemented the WHO STEPWise surveillance program in 2008; however, data on NCD in the Eastern Caribbean is scarce, and prevention and intervention cannot occur if no country-specific data exists. The STEPWise approach could prove useful for Eastern Caribbean surveillance programs.

Table 4. WHO's Standardized STEPWise Method for NCD Risk Factor, Disease, and Mortality Surveillance

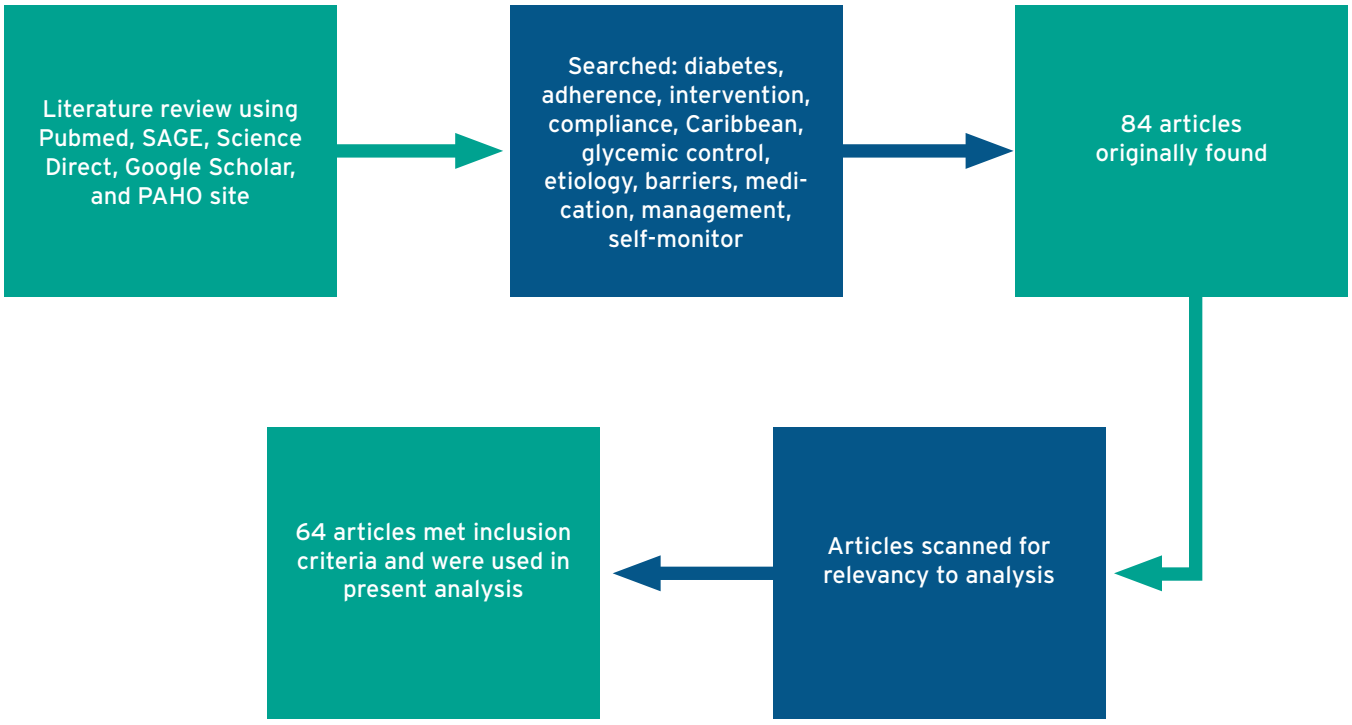
NCD	Step 1	Step 2	Step 3
Risk Factors (the future)	Questionnaire-based report on key behavioral risk factors	Questionnaires + objective physical measurements	Questionnaires + objective physical measurements + biochemical measurements
Diseases (the present)	Hospital or clinic admissions by age and sex	Rates and principal condition by age, sex and principal conditions: communicable diseases, NCDs and injury	Age, sex, and cause-specific disease incidence or prevalence
Deaths (the past)	Death rates by age and sex	Death rates by age, sex and broad cause of death (verbal autopsy)	Death rates by age, sex and cause of death (death certificate)

Source: WHO, 2003b

In addition to the WHO STEPWise model, PAHO, anticipating the rise of diabetes and other NCDs in the Caribbean, assembled a report on the status of surveillance titled, *Networking for the Surveillance of Risk Factors for Non-Communicable Diseases in Latin America and the Caribbean*. The document contains useful information for monitoring trends, the distribution of risk factors, program interventions, and policies specifically for Latin America and the Caribbean (PAHO, 1999).

Having established that diabetes mellitus is a regional threat, nations now must respond using upstream interdepartmental policies in collaboration with downstream health sector undertakings. Widespread, population-based policy can be a very effective tool, as seen with the Trinidad CDAP initiative. Effective interventions require the support of stakeholders outside the health sector, for example those involved in education, agriculture, urban planning, transport, and trade (Hospedales et al., 2011). With the swelling diabetes epidemic and multitude of well-studied intervention options available, the Eastern Caribbean nations must raise diabetes as a national priority, despite its lack of resources, and overcome barriers to care and improve overall health.

Appendix 1. Flowchart of Research Activity



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