Toward Effective Dengue Fever Surveillance and Case Management in the Dominican Republic: Perceptions from Patients, Practitioners and Policy-Makers

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TOWARD EFFECTIVE DENGUE FEVER SURVEILLANCE AND CASE MANAGEMENT IN THE DOMINICAN REPUBLIC: PERCEPTIONS FROM PATIENTS, PRACTITIONERS AND POLICY-MAKERS

By
Deborah D. Roque

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TOWARD EFFECTIVE DENGUE FEVER SURVEILLANCE AND CASE MANAGEMENT IN THE DOMINICAN REPUBLIC: PERCEPTIONS FROM PATIENTS, PRACTITIONERS AND POLICY-MAKERS

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Leading among arboviral disease morbidity and mortality is dengue fever with an estimated 390 million infections a year of which 96 million present clinical manifestations. In the Dominican Republic (DR), dengue fever is endemic where high incidence and outbreaks continue, with the most recent epidemic occurring in 2015. Failed prevention and control efforts have placed an onus on early diagnosis and treatment to aid in surveillance and help reduce dengue disease burden. This study explored dengue care, management and prevention perceptions among three main actors of the dengue diagnostic-management-surveillance scheme: patients, practitioners, and policy-makers. Participant observation, structured interviews, semi-structured interviews, and focus groups were conducted to achieve this aim. Resulting themes provided a deeper understanding of the issues in dengue care, management, and prevention among the three groups of actors, offering sociocultural and political accounts of dengue fever realities in the DR related to the diagnostic-management-surveillance scheme that can be used in policy and decision-making aimed at dengue fever disease mitigation.
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Chapter 1

Introduction

Leading among arboviral disease morbidity and mortality is dengue fever with an estimated 390 million infections a year of which 96 million present clinical manifestations (Bhatt et al. 2013; Achee et al. 2015). In the last fifty years, dengue fever incidence has increased thirtyfold and has spread to new countries throughout the tropics (WHO 2009; Anne-Murray et al. 2013). The regions of highest risk are Asia and the Americas (Bhatt et al. 2013), with the highest incidence occurring within the Americas (Cafferata et al. 2013). Developing countries, such as those found in Latin America and the Caribbean (LAC), provide ideal conditions for dengue fever’s re-emergence, geographic spread, and increase in incidence rates in the past few decades. These are due to conditions that arise from the interaction of the environmental, social and political spheres.

Most countries in the LAC lie within the tropics, which provide ideal environmental conditions, such as plenty of rain, humidity and shade, for the proliferation of mosquitoes. Rapid and unplanned urbanization, population growth, increased inadequate municipal services, and globalization provide more opportunity for transmission (Kendall et al. 1991; Spiegel et al. 2005; Goméz-Dantés and Willoquet 2009; Gubler 2011). Historical and modern unsuccessful interventions in LAC have created political tensions and a sense of distrust between governments and citizens, establishing a blaming culture for who is ultimately responsible for the presence of dengue within communities, attitudes which have promoted impractical approaches to dengue prevention and control. After World War II, many governments in LAC
supported *Aedes aegypti* control programs hoping to reduce yellow fever and dengue (Gubler 2002). In the 1970s, successful control led to elimination and consolidation of programs. Governments, and the public, became content with the success of their efforts. Many regimes did not see the need to sustain such expensive programs in the seeming absence of disease, and, over time and through negligence, dengue fever continued to be a threat albeit a largely invisible one (Spiegel et al. 2005; Gubler 2002; Anne-Murray et al 2013). When dengue began to re-emerge in the 1980s, limited resources and fiscal issues led to unsuccessful efforts while the pressure to find quick solutions led governments to shift the onus of control and prevention onto communities (Gubler 2002; Pérez-Guerra et al. 2005; Pérez et al. 2007; Morrison et al. 2008). Thus, prevention and control strategies went from being vertical to horizontal, placing the responsibility on people to keep their proper homes and environment free of breeding sources.

Unfortunately, these horizontal efforts have been largely unsustainable and ineffective, with the exception of a few cases. In LAC and Asia, Cuba and Singapore provide leading examples of successful dengue control and prevention (Beatty et al. 2010; Whiteford and Hill 2005; Whiteford 2000; Pérez et al. 2007). What Cuba and Singapore have taught us is that dengue prevention and control efforts require interdisciplinary, multi-sectoral, collaboration involving policy-makers, health workers, and community members.

The shift of responsibility to prevent and control dengue went from the government to the public, which created a blaming culture where the government and one’s own neighbors are accused of causing dengue fever within communities (Kendall et al. 1991; Winch et al. 1992; Whiteford 1997; Whiteford 2000; Coreil et al. 2000; Pérez-Guerra et al. 2005). The absence of fogging and poor maintenance of municipal services
within LAC communities, such as in the Dominican Republic and Puerto Rico, leaves people feeling resigned (Whiteford 1997; Whiteford 2000; Coreil et al. 2000; Pérez Guerra et al. 2005). Community members feel powerless without the presence of the government, whose help with consistent fogging and maintaining the environment clean and with constant water supply could boost morale. Communities are expected to prevent dengue by participating in source reduction, with little to no help from the governments. However, the lack of government assistance contributes to sentiments of futility among community members. These attitudes have promoted individualistic, thus unrealistic, approaches to dengue prevention and control (Pérez-Guerra et al. 2005), in addition to causing general distrust and lack of faith toward government, such as in the Dominican Republic (Finkel et al. 2000; Whiteford 2000).

One limitation is that most literature on the sociocultural and political realities of the Dominican Republic is from the 1990s. Since then, little information has been comprised detailing the perceptions and behaviors of local residents and patients regarding dengue fever prevention and control and treatment specifically from a critical perspective. Even less material exists detailing diagnostic and reporting protocol among physicians, and reporting and public information distribution among policy-makers. The scarce literature on these contributes to the shortage of culturally appropriate and sustainable intervention designs. This study aims to provide an updated account of those experiences for use in policy and decision-making schemes aimed at dengue disease mitigation within the Dominican Republic.

Moreover, lack of resources, political strains and unsuccessful prevention and control efforts in the Dominican Republic (DR) (Whiteford 1990,1992,2000) have led to
continuous outbreaks since the late 1990s, with the most recent occurring in 2015. During the dengue fever outbreak of 2015, the DR reported over 100 total deaths. Globally, in the Americas region, the DR has the highest case fatality rate at 1.54% (PAHO 2014). Peru is second with a .12% CFR; the CFR for the entire region is .04% (PAHO 2014). This is a cause for concern and requires particular attention, because the CFR for any region or country should be less than 1%. This indicates a problem with one or several of the following areas with respect to dengue fever in the DR: patient healthcare behaviors, diagnosis, management, reporting, surveillance, prevention and/or control. However, political tensions, government distrust and negative attitudes towards the healthcare sector do not foster collaborative and sustainable circumstances that are not suitable for dengue control and prevention in the DR.

Many studies aim to examine such issues to provide multi-sectorial, interdisciplinary, and integrated solutions (Harrington et al. 2013; Tambo et al. 2016). Vector-disease control and prevention requires multi-level and multi-systemic attention, accounting for the physical and social environmental factors involved in disease transmission. The WHO (2009) has acknowledged the human nature and complexity inherent in vector-borne disease control and has proposed Integrated Vector Management (IVM) as a solution. While IVM seems promising, it must be taken for what it is: a highly systematic approach demanding macro-level implementation and coordination between the intermediate and micro-levels. IVM mentions the need to be aware of sociocultural barriers, but not political ones. Many interventions designed to remove these barriers involve increasing knowledge and skills in hopes of behavioral change, however this is difficult to accomplish. IVM fails to account for the current realities that influence
attitudes and behaviors, which ultimately affect behaviors such as adherence to protocol. Sociocultural and political realities must be understood to break the cycle of negative attitudes, such as distrust and blame, to foster collaborative approaches through updated policy implementation and intervention designs.

This study aims to fill that gap by understanding the sociocultural and political perceptions, along with current policy and practices, in relation to dengue fever in the DR from three primary groups of actors. This will be achieved by understanding, characterizing and analyzing the following in the DR:

1) Current perceptions among patients regarding the role of the government and healthcare centers in dengue prevention, control and management
2) Existing perceptions and practices among practitioners concerning dengue diagnosis and management protocols
3) Current policy along with policy-maker perceptions related to prevention and management within dengue surveillance, diagnostics, and management schemes

The results of this study provide perspectives about the health care system’s management of dengue fever in the Dominican Republic from three primary groups of actors: patients, practitioners and policy-makers. It offers a sociocultural and political account of daily realities and concerns within the dengue diagnostic-management-surveillance scheme. These perspectives can inform researchers, health practitioners, patients, and policy-makers about ways to strengthen protocol and develop trust within
the health care system to foster fluid and sustained collaboration with increased agency
toward disease mitigation.
Chapter 2

Background

2.1 Dengue Virus

Estimating the true burden of dengue fever is difficult due to limitations and barriers with diagnosis and reporting, which are affected by many factors. Dengue virus complexities, varied clinical manifestations of disease, and the lack of a specific therapy make clinical diagnosis and management a challenge for health practitioners. Dengue disease is caused by infection from one of the RNA virus’ clinically important serotypes: DENV-1, DENV-2, DENV-3, and DENV-4 (WHO 2009; San-Martin et al. 2010; Pone et al. 2016). A fifth serotype, DENV-5, has been identified though its clinical importance has not yet been determined since there is no reported sustained transmission of DENV-5 in humans (Normile 2013). Infection by one serotype can grant the host with immunity from that specific type, however re-infection with another strain can potentially cause complications (WHO 2009; Verhagen and De Groot 2014; Katzelnick et al. 2017). The most ideal solution is vaccination. In past years, varying serotypes have made vaccine development difficult. Today, there is promise with the first dengue vaccine, developed by Sanofi Pasteur, which is currently undergoing Phase III clinical trials and registered for use in individuals 9-45 years of age in endemic countries (WHO 2016). For now, the vaccine is an expensive investment and a cautiously optimistic option as it remains uncertain what its long-term effects will be. Thus, efforts to reduce dengue morbidity and mortality must continue to rely on timely diagnosis and management, surveillance and prevention/control efforts.
2.2 Dengue Diagnosis and Clinical Management

At the healthcare level, the absence of a cost-friendly and globally available vaccine means reduction in dengue fever caseloads has relied upon clinical diagnosis and management. Typically, dengue fever is characterized by its symptoms: fever, arthralgia, myalgia, rash, and retro-orbital pain (WHO 2009; Katzelnick et al. 2017). When present, these symptoms are non-specific and can be confused with other febrile illnesses, such as flu and malaria (WHO 2009; Stoler et al. 2014), and, more recently, with Zika and Chikungunya (Katzelnick et al. 2017). Thus, laboratory confirmation is necessary. Only acute-phase diagnostic tests, such as viral PCR, can be truly useful in clinical management. However, high costs and low human resource capacity render these tests futile in resource-limited settings (Beatty et al. 2010; Katzelnick et al. 2017). While few cases of dengue fever are clinically diagnosed, even fewer are confirmed with laboratory tests (Horstick and Morrison 2014). Often times, IgM/IgG ELISAs are used for confirmatory diagnostics, but samples are collected after the 5th day of fever onset and results are not used for timely clinical management (Katzelnick et al. 2017). To effectively decrease dengue morbidity and mortality early detection and timely management is critical (Tomashek et al. 2014; Pone et al. 2016; Katzelnick et al. 2017).

The WHO’s (2009) dengue classification scheme was created to help practitioners follow and better manage the different manifestations of the illness. The purpose of the revision was to facilitate clinical triage of dengue patients by classifying dengue’s level of severity, distinguishing between mild dengue and severe forms of dengue (Kit Lam 2013). The current case definition is divided into two groups: dengue with/without warning signs and severe dengue (WHO 2012). Dengue warning signs “warn”
practitioners that the illness can evolve to severe dengue if immediate and proper treatment is not administered. Dengue without warning signs is diagnosed as probable dengue and associated symptoms include fever and two other of the following: nausea, vomiting, rash, aches, pains, leucopenia and any warning sign. Laboratory confirmation should ideally be done at this time, when no plasma leakage is present. Dengue with warning signs include abdominal tenderness/pain, persistent vomiting, mucosal bleeding, fluid accumulation, lethargy, restlessness, and liver enlargement of greater than 2 cm. Laboratory tests at this point can show increased hematocrit with rapid decrease in platelet counts. The diagnosis evolves to severe dengue when there is severe plasma leakage (which leads to shock or respiratory distress), severe hemorrhage, and severe organ impairment.

Despite the new classification scheme, problems with dengue diagnosis and management persist. Since its publication, the WHO scheme has been criticized for providing broad guidelines, thus suffering from low specificity and sensitivity (Kit Lam 2013; Runge-Ranzinger 2016), which can lead to misdiagnosis. Others have concluded that the scheme has its advantages for clinical and epidemiological use (Horstick et al. 2012). In the end, the responsibility lies upon the physician to successfully interpret the protocol for correct diagnosis and timely management. One problem associated with the management protocol is fluid control (Whitehorn and Farrar 2010; Horstick et al. 2015). When a patient is in shock, fluid rehydration, electrolyte management and patient monitoring is most important. It has been noted that a few cases of fluid overload are inevitable (WHO 2012) in the management of severe dengue, which can attribute to deaths (Tolle 2009).
Moreover, timely diagnosis depends on patient healthcare behaviors. Common febrile illnesses, such as the flu, are generally not viewed as threatening, so patients with mild illness will typically avoid seeking care and will self-treat and auto-medicate at home (Kendall et al. 1991; Whiteford and Hill 2005; Khun and Manderson 2007; Pérez-Guerra et al. 2009). Additional delays in treatment-seeking arise from structural, institutional, and economic factors. In impoverished areas these include access to healthcare facilities, time and cost of transportation, quality of care, and cost of medication (Khun and Manderson 2007; Horstick et al. 2015). Reducing case fatality from severe dengue requires early intervention, but if patients are not being diagnosed properly, or are coming in too late to seek care, then prospects for recovery are grim. These issues also have broader consequences, since early and accurate diagnosis is paramount for effective passive surveillance systems.

2.3 Dengue Surveillance

Dengue surveillance systems are necessary for early outbreak detection, to inform vector control and prevention, and to monitor disease trends (Runge-Ranzinger et al 2014). This cannot be achieved when the quality of available data for dengue is poor resulting in a large gap between reported and estimated cases (Horstick and Morrison 2014). Surveillance data must be available for routine control methods, but they are usually not applied properly or maintained resulting in a lack of coordination between surveillance and response teams (Horstick and Morrison 2014). Part of the problem is defining who is required to report and within what time frame. One study found that out of 14 countries with outbreak response plans, half did not include that all health units
were required to report (Harrington et al. 2013). This means that while public health facilities may be required to report, private facilities are not. This selective reporting process adds to under-reporting, which can misrepresent dengue disease trends and enable complacency. Another study concluded that there are high levels of under-reporting of dengue, specifically for ambulatory cases, and it is unclear how much under-reporting endemic countries can tolerate before affecting disease trends and early outbreak response (Runge-Ranzinger et al. 2014). Furthermore, monitoring and evaluating whether all health-care facilities are reporting as required should be a national priority; surveillance of infectious diseases is a country’s responsibility. Effective surveillance aids in the development of public health policies and guidance of disease intervention (Thacker and Stroup 2006; Nsubuga et al. 2006), while ineffective or inconsistent surveillance systems contribute to the re-emergence of disease (M’ikanatha et al. 2007), by negatively impacting prevention and control programs.

2.4 Vector Prevention and Control

Reducing dengue virus transmission relies heavily on prevention and control measures that target the mosquito vector (Katzelnick et al. 2017). Such efforts, globally, have been mostly unsuccessful due to inadequate implementation and inconsistent routines (Horstick et al. 2015; Runge-Ranzinger et al. 2014). These issues are influenced by lack of personnel, lack of funds, lack of expertise, and difficulty engaging the community, among other factors (Runge-Ranzinger et al. 2016). Other barriers to successful vector control include mosquito resistance to chemical interventions, such as use of Temephos larvicide (Chen et al. 2013; Rodriguez-Roche et al. 2013; Ocampo et al.
Due to these problems, most prevention efforts are community oriented and focus primarily on eliminating breeding sites (Katzelnick et al. 2017). Such interventions have variable degrees of effectiveness. In recent years, combined community interventions, such as use of insecticide-treated nets together with participation in cleanup and educational campaigns, have impacted vector indices (Bowman et al. 2016), but remain challenging to implement. Novel vector-control strategies such as the use of genetically modified mosquitoes infected with Wolbachia (Wilder-Smith and Macary 2014; Horstick et al. 2015) seem promising, though some concern remains regarding the possibility of dengue viruses evolving to become a greater public health risk (Murray et al. 2016). Overall, the best practices in vector control and prevention for any specific affected area is difficult to define (Runge-Ranzinger et al. 2016) since there is no such thing as a single solution for all.

Globally, combating the burden of dengue disease has become more complicated since dengue’s re-emergence. In today’s urbanizing world where cities are becomingly increasingly densely populated with rapid, unplanned urbanization, it is no surprise how the *Aedes* spp. mosquitoes are able to adapt successfully and how disease transmission is sustained. Of all the global cases, successful dengue prevention and control efforts in Cuba and Singapore are exemplary (Whiteford 2000; Whiteford and Hill 2005; Pérez et al. 2007; Beatty et al. 2010), but their methods are suitable within their local context. Dengue realities differ among countries, and among communities, which affect dengue intervention policy and approaches.
2.5 Dengue Realities in the Dominican Republic

The Ministerio de Salud Pública (MSP), or Ministry of Public Health, is in charge of the Dominican Republic’s health system and is represented by regional governing authorities (WHO 2016). The overall health system is decentralized in nature, which inherently gives regional authorities a certain amount of autonomy. There are eight regional health areas, numbered from 0-VIII, where the Direcciones Provinciales de Salud (DPS), or Provincial Health Directorates, acts as local governing health bodies. There are 43 in total: 32 for each province plus 8 in the National District of Santo Domingo and 3 in Santiago. The DPS in Santo Domingo and Santiago are called Direcciones de Areas de Salud (DAS) (this study does not differentiate between the DPS and DAS because they have the same function). In 2015, the Dominican Law 123-15 created the Servicio Nacional de Salud (SNS), or National Health Service, to help ensure technical, financial and administrative aspects of health services (WHO 2016). This lifted some responsibility off the MSP, though the MSP still serves as the main governing body. One of the MSP’s responsibilities is surveillance. The MSP requires dengue fever to be reported within 24 hours. All reports must go to the Dirección General de Epidemiología (DIGEPI). DIGEPI publishes suspected, confirmed and defunct dengue cases in their weekly bulletin. Dengue surveillance in the DR is passive, relying on health-care providers to report cases of disease. Surveillance depends mostly on the public health sector and the National Laboratory. It is unclear to what extent the private sector is involved within the reporting aid overall surveillance system.

In the DR, power plays and political and economic crises affect the public health system and negatively impact dengue prevention and control efforts (Whiteford
1990, 1992, 2000). For many years, the government has been unable to respond to the problems in the health sector due to issues with underutilization of facilities, lack of personnel training and capacity, and issues of political patronage (where decisions for health budgets, personnel, and policy are made based on the preferences of presiding Presidents and political affiliation of officials) (Whiteford 1992; Glassman et al. 1999; La Forgia et al. 2004). Furthermore, the DR suffers from inadequate electricity and distribution of potable water and poor sanitation, which has negatively impacted dengue prevention and control efforts. With time, Dominican citizens began to distrust their government with respect to health, feeling that all the government did was make empty promises (Whiteford 1997, 2000). Policy-makers and government officials are expected to aid the community, however many politicians and government officials are accused of being corrupt, robbing from the system and acting in self-interest.

Critical barriers to disease control and prevention arise from the differences between policy-makers, researchers, and communities, which interferes with knowledge exchange and cooperation needed for sustainable program development and implementation (Spiegel et al. 2005). For any disease prevention and control intervention to be effective and sustainable, structural, institutional, political and behavioral issues associated with the prevention and control of infectious disease must be dealt with systemically (Manderson 1998). Prevention and control efforts must also use a critical lens to examine local contexts to understand the specific political and cultural phenomena influencing interventions, behaviors, and policy.

In the DR, the greatest amount of responsibility is placed on communities for dengue prevention—a consequence of limited resources and of the shift of dengue
mitigation strategies from being vertical to horizontal. The MSP hopes to empower people to take charge of reducing mosquito-breeding sources in the home and around the community. To help with this, at the national level the MSP broadcasts prevention messages such as “*salud somos todos*” or “we are all responsible for our health” and “*cloro untado, tanque tapado*” or “bleach applied, container covered,” which try to convey a community sense of health while addressing mosquito breeding sources within the home. The MSP also wants for people to seek care at UNAPs or other health centers more often. At the provincial level, the DPS organize groups of *promotores de salud*, or health promoters, who are responsible for visiting households and providing educational material. Sometimes the *promotores de salud* are tasked with actively searching for febrile cases and following-up to see if the person sought care and recovered. The DPS are also in charge local dengue prevention campaigns, which involve looking for *criaderos*, or breeding sources, and educating the public on how to prevent mosquitoes from laying eggs in the family water storage tanks and other clean water reservoirs in and around the home. The inadequate water supply has created a large water-storage culture where families must keep various water-storage containers for when the water does not arrive, which can last weeks in some barrios. Furthermore, not all communities have the advantage of having a locally engaged DPS in the province. Many community members, especially those who live outside the capital, claim to rarely (if ever) see MSP workers of any kind. Communities with limited or an absence of government presence often struggle with dengue prevention and control, along with other health concerns. These communities tend to be more marginalized and have less access to healthcare; many
travel to the capital or to Santiago, the two largest cities, for medical emergencies due to the lack of tertiary level hospitals within or near their provinces.

There are three levels of healthcare in the DR: primary/community, secondary/municipal, and tertiary/provincial. At the primary level, there are Unidades de Atencion Primaria (UNAPs), which should be a patient’s first contact center for non-emergency cases. At the secondary level, there are public and private hospitals. These hospitals have an emergency ward, but lack many medical specialties. At the tertiary level exist private and public referral hospitals, which often become over-crowded with patients that are transferred or who skip seeking health first at the primary and secondary healthcare centers.

Within health centers, the responsibility lies on doctors for timely clinical diagnosis and management of dengue fever cases. During periods of high transmission or outbreak, this is a challenge. For instance, at the primary level, the UNAPs are usually employed by one nurse and one pasante. Pasantes are recent medical school graduates completing a year paid-internship of community service. All doctors must enter pasantia if they expect to apply for residency. Thus, the UNAPs are directed by newly minted doctors with little clinical experience who actually obtain the bulk of their experience as the “head” of an UNAP. Often times there is a shortage of supplies, medications, and personnel within primary and secondary healthcare centers. This influences local residents’ health-seeking behavior: whether or not to visit local primary and secondary healthcare centers. Such issues lead residents to often distrust their local healthcare centers and opt to travel to the larger cities to acquire better attention. This can be problematic since it can cause over-crowding at the tertiary level and can affect patient
treatment and management. During a dengue outbreak, the travel delay and need for transfers, due to lack of equipment and supplies, exacerbate untimely care leading to complication of cases and death.
Chapter 3

Methods

3.1 Study Area

The fieldwork for this study began immediately after the 2015 dengue fever outbreak in the DR, which occurred during the second half of that year. The capital city of Santo Domingo was one of the areas significantly impacted. Santo Domingo is located on the southern coast of the island. It is divided into two provinces: the Distrito Nacional (DN) and Santo Domingo; the Santo Domingo province is divided further into seven municipalities. Both provinces are additionally divided into dozens of sectors. As a whole, the capital of Santo Domingo holds a population of about 2,374,000, with the population of the DN accounting for 35% (ONE 2012). The Distrito Nacional is the “national district” where the Presidential office (Palacio Nacional), Congress, Supreme Court, and central ministries (Ministerios) are located. It is also the site of some of the most advanced and recognized tertiary level hospitals. Part of the investigation took place at a pediatric referral hospital in the DN, within the sector of the Centro de los Heroes. It is one of the only national reference hospitals for pediatrics, meaning all emergency and severe pediatric cases are referred there in addition to its daily flux of cases. It is widely renowned in the country and served as a hotspot for dengue fever cases during the outbreak. The hospital is also a teaching hospital, housing one of the largest pediatric residencies, including sub-specialties, in the country. Another part took place in the sector of Los Ríos, within a semi-private, specialized hospital. This hospital is a patronato, which means that they are sponsored by a foundation formed by employees: the doctors. This hospital also serves as a teaching hospital for medical students and
residents. The hospital specializes in medical education, care and management of diabetic patients while providing standard hospital services for those in need. During the Chikungunya outbreak of 2014 this hospital was greatly affected and it was expected that the same would occur during a dengue outbreak—though this did not occur. The remainder of the study was conducted within the MSP at the Vice-Ministry of Collective Health, the office which is responsible for creating, carrying out, managing, and evaluating all public health programs including dengue fever surveillance, prevention, and control.

3.2 Study Populations

Surveillance systems have three principle actors: community members, healthcare professionals, and policy-makers. Community members who seek health care for dengue fever are registered in the hospital system whose diagnosis is reported by physicians to the Dirección General de Epidemiología (DIGEPI), which publish disease burden statistics and use the information for public health decision-making. Adequate public health decisions and emergency response cannot be achieved within surveillance systems without efficient and effective participation and coordination among all three of these actors.

At the pediatric center, patients from all over the country traveled to exclusively seek care at that hospital, whether by reference or choice, providing broad diversity in hospital attendees. Many patients that arrive to seek care at the hospital come from low socio-economic backgrounds having traveled long distances from other provinces. The majority of patients arrived using public transportation or carpooling. Due to the delicate
nature of the patients and the emotional states their families were in, convenience sampling was used for selecting focus group participants based on their availability and willingness to participate. The probability of parents agreeing to meet at a specific time and place for a focus group was not likely.

Resident doctors were in charge of managing patients within the hospitals. Head doctors were only present during rounds, where they would ask for patient updates, use the patient’s case for teaching, and take the opportunity to change a patient’s management scheme or medications. Most of the head doctors were not around after lunchtime; many had other responsibilities to attend to outside of the hospital. Some had private practices or were professors, while others had political assignments or had commitments with other hospitals. Thus, resident doctors were selected to participate in focus group discussions and structured interviews based on their contact time with patients and accessibility. At the public pediatric hospital, it was harder to schedule times for the focus groups and structured interviews with the residents. Convenience sampling was eventually used due to the heavy workload of the doctors.

At the MSP, interview subjects were snowball sampled, where one high-ranking government official who had a role within the dengue programs would refer the next government official. Each participant maintained an active role related to the dengue programs within the country. All interviewees had senior positions within the Ministry and its decentralized branches with the exception of one interviewee who worked at the local PAHO division.
3.3 *Data Collection*

Participant observation allowed me to integrate and understand the general Dominican political and health culture within hospitals and the MSP. Participant observation, which included use of informal interviews, was conducted at the within the MSP and at the clinical level within the study hospitals to build rapport and closely observe and record the daily practices, behaviors, and perceptions regarding dengue fever clinical management, reporting, and surveillance. Focus group discussions were conducted with the parents of pediatric patients, to assess general health concerns, care and prevention regarding dengue fever, and the role the Dominican government has in their communities. To understand the reporting protocol within the DR and the barriers to achieving successful surveillance community members, physicians were selected for structured interviews and focus group discussions, while policy-makers were selected to participate in semi-structured interviews.

Before beginning the interviews, questionnaires, and focus groups, each participant was read a verbal consent script in Spanish. The verbal consent form guaranteed anonymity and confidentiality by assuring the participants that all identifying information would *not* be used in publication. The verbal consent form also indicated that participation was voluntary, and any participant was free to stop the interviews or leave the focus groups upon their discretion without consequence. Additionally, the consent script assured participants that only the study investigators would have access to the data. My contact information was offered for further questions or to obtain a copy of the audio-recordings.
Each interview and focus group was conducted in Spanish and audio-recorded with permission from all participants, with the exception of the structured interviews that were not recorded. In the field, test interviews and focus groups were conducted to ensure the validity of the questions. Some questions were re-worded or changed to assume a more culturally appropriate language and style. All interviews were conducted with permission from the participants. Verbal consent scripts were written for all interviews and were read aloud prior to starting each session (see Appendix A). All participants agreed to the verbal consent script prior to beginning. No participants declined participation, and few participants within the focus groups left early.

Participant observation (PO) and informal interviews were a central element of inquiry in this research study. Within the two study hospitals, data was collected using participant observation during weekly visits. Mornings were the best times to conduct PO because all the head doctors were present for rounds. By lunchtime, hospital activity would considerably slow down. In the late afternoon, between 3-4pm, the overnight shift would enter leaving only about 20% of its resident doctors left to care for the whole hospital until the next day at 7:30 am, when the shift change would occur. For months I spent time in the emergency department, recording daily interactions and procedures. Once I achieved a level of saturation, I moved to the dengue ward. Only the pediatric hospital had a dengue ward where I could continue to conduct the PO. This hospital also had an epidemiology department, which I also visited often to conduct PO, that was in charge of reporting all dengue cases to DIGEPI. Within the Vice Ministry of Collective Health in the MSP, I asked permission to conduct PO within the Dengue Team’s office, the Oficina Desconcentrada de la Gestion de la Rectoria, and CENCET. I spend most of
my time with the Dengue Team and CENCET because they were more directly involved with the subjects of auditing the dengue deaths and prevention and control. I also spent some time within one of the DPS to understand how the epidemiologist plays a role in dengue reporting and community interventions. PO provided occasions for opportunistic informal interviewing and discussion of current policies, practices, and perceptions related to the different dengue programs and their functionality. This offered profound insights on the topics and served as a comparison to the recorded interviews. All entities were aware of the project I was conducting and volunteered their time and information to help with my study aims.

Focus groups were conducted in the pediatric hospital with resident doctors and community members, or patients (see Appendix B, Table 1 and Table 2). The hospital’s resident doctors were ranked according to their year of residency: Resident 1 (R1), Resident 2 (R2), Resident 3 (R3), and Resident 4 (R4). Each year has different responsibilities with an established hierarchy in roles and management. One focus group was conducted per rank; grouping each rank together provided a space for residents of the same year to talk freely within their cohort without worrying about challenging or condescending other ranks. The focus groups explored resident’s responsibilities, barriers to providing care, and dengue clinical diagnosis, management and reporting protocol within the hospital.

The community member focus groups were conducted with hospital patients of the pediatric hospital due to its status as a national reference center. An R4 helped me solicit focus group participation of parents. The four focus groups ranged from 7-12 participants and lasted between 45-60 minutes. The topics discussed included perceptions
regarding general health concerns within their communities, dengue fever treatment and health seeking behavior, community dengue prevention and control and the government’s role in health care. Four community member focus groups were conducted in total.

Additionally, structured interviews (or verbal questionnaires) were administered to resident doctors within both hospitals. A total of 50 questionnaires were completed. In both cases, the chief resident doctor helped me obtain resident contact information and, in some cases, helped me find an available resident to interview. I expected to interview all residents at both hospitals. At the semi-private hospital, a total of 26 interviews were conducted; the hospital only had 27 residents, thus only one interview was not completed. At the pediatric hospital, a total of 24 interviews were completed. The questionnaires focused on dengue fever clinical training, diagnosis, management and reporting protocols. The questionnaires were a way to try to quantify resident responses, however the small sample size obligated me to analyze the data qualitatively like the rest.

Semi-structured interviews were used at the MSP level with select policy-makers and directors involved in dengue surveillance, prevention, control, and management (see Appendix B, Table 3). Interview times ranged between 30-90 minutes and the interview topics focused on dengue reporting, surveillance, prevention, and control. The interviews were conducted within the subject’s respective government building and office.

3.4 Instruments

I developed all questionnaires and the interview and focus group scripts; each were reviewed and edited by my committee members. I also translated them all into Spanish, and a paid translator conducted the back-translations.
The community member focus group guides contained 8 questions, each including 1-3 probing questions that were only asked if necessary (see Appendix C). Two questions involved asking about general health concerns and the role of the government had in community health. One question asked about the relationship between the MSP and the community specifically. Three questions asked about dengue risk and community prevention. One question asked about treating dengue and the last question asked to describe the perceptions of doctors and nurses in dengue care.

Practitioner focus group scripts contained 7 questions, again with 1-3 probing questions (see Appendix D). Three questions explored dengue clinical diagnoses and management. Two questions asked about dengue reporting. The last two questions asked about suggestions for improving diagnostics, management, and reporting within the hospital.

The physician structured interview questionnaire contained 42 questions (see Appendix E). Some responses already had predetermined answers, with either single or multiple selection options, and with the opportunity to answer “other” and provide an open-ended response. A few questions were designed only be an open-ended response, while some were Likert scale styled questions. The physician questionnaire asked about general demographic information, dengue training, dengue clinical and laboratory diagnosis, and dengue reporting.

Policy-maker semi-structured interview scripts contained 9 questions along 5 themes: warm-up, grand tour, dengue control and prevention, community relationships and final evaluation (see Appendix F). The semi-structured interview also included a section of 8 additional possible probing questions. Each question also included 1-2
probes. The warm-up section included 3 questions about the interviewee’s role and training. The grand tour section contained 3 questions focused on dengue surveillance. There was one question on dengue prevention and control and one question on community and government relationships. The final question asked interviewees to make suggestions to improve dengue surveillance.

3.5 Data Analysis

One year was spent in the field collecting data from 2016-2017 in Santo Domingo, DR. Three composition notebooks were filled with participant observation notes, and over 16 hours of interview data was collected. Eleven semi-structured interviews were conducted with MSP directors and policy-makers, four focus groups were conducted with resident doctors, and four focus groups were conducted with the parents of admitted patients. All interviews were completed and audio-recorded. Fifty structured interviews were completed with health practitioners. Thematic analysis resulted in over 3,500 coded segments from which themes emerged.

All audio-recorded data from the semi-structured interviews and focus groups were transcribed and translated into English by me. The transcriptions and all notes from PO were digitized and uploaded onto the MaxQDA v.11 platform for qualitative data analysis. Structured interview data was uploaded onto Excel where open-ended answers were transferred to a word document and also uploaded into MaxQDA.

Braun and Clarke’s (2006, 2013) model for thematic analysis was used as a guide for inductively discovering research themes. The guide provides a broad and robust systematic framework for coding text that can be widely applied in the social and health
sciences (Braun and Clarke 2014). The aim of thematic analysis is to create various clusters of themes instead of developing main core categories (Ngulube 2015). These clusters are then compared and grouped into larger, similar clusters forming broader thematic spheres. The larger themes are broader and illustrative in nature, revealing relationships between the various subthemes.

Adhering to Braun and Clarke’s model, I used 6 steps in the overall analytical process. The first step was familiarization with data. This was achieved during the data collection and analysis process. I conducted all the PO, focus groups, questionnaires and focus groups within the study, granting me first exposure to all the data. Then, I listened to all the audio-recordings from the focus groups and interviews and digitized all PO notes. Collectively, there were over 350 typed pages of text generated. This allowed me to become comfortable with the data set and make general observations. The second step was coding. I individually read each document, and as I read I began to inductively label sections of texts. The latter involved reading the text and allowing theory to emerge from the coding process. Themes emerged based on the number of coded segments a label had. Each time a label/code is defined/used, that number is shown next to the respective label within the code box. Labels with a higher number of coded segments indicated a pattern. This led into step 3: searching for themes. This was where broader labels were created so that the already coded segments could be collated within them to generate a theme. It was an iterative process that involved reading over coded segments and creating specific memos for each of the labels. Labels that were related or similar were then collapsed together into groups. The memos provided a description of the codes, and the inclusion and exclusion criteria of each code. These memos helped ensure that the sub-coded items
that were collapsed together fit the criteria of the specific group/code. This allowed me to keep the coding and thematic analysis more controlled. Created groups that resulted in a high number of coded segments began to create themes. Various themes were created, which led to step 4, reviewing each theme. This required scrutinizing already created themes and re-reading coded texts to make sure the themes fit together well. I also consider this a form of data cleaning. In this step, the memos allowed me to better define and name larger themes, which was step 5. Here I began to organize my themes and write descriptive information in the memos that defined the core of each and how they all connected to create a larger narrative. The last step is “writing up” this narrative, which should be a culmination of the analytical document extracts linked together to tell a story about the data. This was not a linear process, but a recursive one that sometimes required me to repeat one step more than another.

The thematic analysis technique allowed for a fluid and flexible method of data analysis that did not confine the analysis to strict coding guidelines, but rather allowed me to freely identify patterns across the data set for applied use. Thematic analysis helped me understand larger over-arching national themes along with nuanced social and political themes that are specific to the DR. The themes generated can be readily presented to non-academic audiences and used for policy change.

3.6 IRB

This study was supervised by the University of Miami’s IRB, protocol #20140009. The study was approved March 2016 and closed in September 2017. Additional formal
oversight was provided by the Research Committee at the supervising hospitals (hospitals names withheld to ensure privacy).
Chapter 4

Results

The following, resulting themes are organized by sector: national, hospital, and community. The quotes provided were carefully selected using the MaxQDA software. All documents were activated along with relevant and specific codes, which allowed me to search for the most representative quotes related to each theme.

Each sector contains one macro-theme and one micro-theme. Macro-themes are over-arching themes describing broader events and motifs affecting the sector as a whole, while the micro-themes describe more nuanced social and political perceptions related to the macro-theme.

4.1 National Level

4.1.1 Macro: Characterizing Dengue Deaths

This subsection provides further context related to the events following the dengue outbreak of 2015. The following information was gathered through PO, and provides important background that helped drive the national and local discourse regarding dengue fever in the country during the time of the study that influenced participant responses.

The responsibility of the DR’s surveillance system is to capture suspected, probable and confirmed hospitalized and ambulatory cases of dengue fever. When dengue fever is detected it is mandatory to report the disease within 24 hours. The passive reporting system relies on healthcare facilities to upload all cases to the Sistema Nacional de Vigilancia Epidemiológica (SINAVE) using a standardized form called the Modulo de
Vigilancia Especial Formulario Unico de Notificacion Individual de Caso—the Special Surveillance Module Single Individual Case Reporting Form (commonly referred to as Epi 1). Passive surveillance systems typically suffer from under-reporting. In the DR, it is widely recognized that ambulatory cases are not usually reported. Of the hospitalized cases that are reported, laboratory confirmation is not required. More importantly, cases of mortality caused by “probable dengue” or “probable severe dengue” were reported and published without laboratory confirmation. The 2015 outbreak changed this. During this time, once the death toll reached a specific, undisclosed number, the national surveillance system stopped reporting until they could confirm the deaths. By this time, the number of mortalities was affecting the nation’s case fatality rate—giving the DR the highest CFR of the LAC region. The high death toll also caused social and political controversy, where the media blamed the government for lying and trying to hide the true numbers. The President and the Ministra took priority in finding a solution. The discussion and events that resulted after the outbreak in the DR helped drive the research by serving as a central and current topic, nationally. The following is a brief description of these events, which help set a context for the results presented later.

To audit and reduce deaths within the healthcare sector, in August of 2015 the Ministra created the Program for Prevention and Control of Dengue, Chikungunya, and Zika, commonly known as the Dengue Program. The Dengue Program consisted of a committee with three members: one general medicine physician, one pediatric physician, and a dengue expert with Dr. Med and MSc (CHDC) credentials. The program held a prestigious place within the Office of the Ministra, where the team worked tirelessly to collect all case files of the deceased from the health centers where the death occurred.
This was done with the help of the *Oficina de Coordinación de la Gestión Desconcentrada de la Rectoría* (Office of Coordination of the Decentralized Management of the Directorate) who would solicit a copy of the physical case file and turn it in to the Dengue Team.

Once the file was obtained, the Dengue Program’s responsibility was to audit each case to confirm or discard the cause of death by dengue. The Dengue Program scheduled weekly Thursday meetings to conduct the audits with a review board. The board consisted of Dengue Program members along with selected medical specialists from pediatrics, internal medicine, and infectious diseases. In order to conduct the case audits, at least 3 specialists and 2 Dengue Program members were required to be present. The audits required that each case file contained the following information: name, age, province, name of hospital(s), medical records, verbal autopsy, medical autopsy, certificate of death, and test results from the National Laboratory. During the audit meeting, the doctors discussed key patient vitals such as levels of blood pressure, heart rate, respiratory rate, whole blood count, hematocrit, platelets, hemoglobin, albumin, protein, and liver transaminase. The team also examined fluid balance, medications, temperature, urine output, clinical diagnosis (probable dengue or probable severe dengue), evolution, management and cause of the death (i.e. septic shock, organ failure, pulmonary edema). A conclusion was then reached: confirmed as dengue, discarded, or inconclusive. Confirmed cases were further classified into preventable or not. If the confirmed case was deemed preventable, the Dengue Team would visit the hospital where the mortality occurred to discuss the patient’s death and provide recommendations for improving clinical management. All confirmed cases were reported to DIGEPI for
publication. Inconclusive cases were those with insufficient information to determine if the cause of death was attributed to dengue fever. In those events, the Dengue Team would personally ask the hospital for a more complete file for re-review. If files were only missing the verbal autopsy and serology results—assuming they were conducted—if they arrived, then the case would be re-opened for a follow-up discussion. This was done for all cases of mortality.

To prevent deaths, the Presidency ordained the *Jornada Nacionales de Descacharrización*, or National Clean-Up Campaigns, which began in January of 2016. The national campaigns were social efforts of prevention organized at the provincial level, and conducted by public workers, to remove *criaderos*. The DPS would coordinate with local government entities and form groups that would visit vulnerable sectors. The groups would meet in a specified location and then break up into smaller units for better coverage. The units were responsible for distributing flyers, *abater* (Temephos larvicide), and helping businesses and home eliminate *criaderos*. The campaigns were scheduled for the third Friday and Saturday of each month from January to June. In July, the campaigns were scheduled every Friday and Saturday. In August, they stopped. Entomological surveys were conducted to try to measure the efficacy of the *jornadas*, but not all were conducted on time thus rendering the data questionable. In September, once again, the responsibility of prevention and control would rest upon the individual provinces and their communities.
4.1.2 Micro: Inexperience

Contributing to dengue deaths was lack of physician experience regarding dengue clinical management. Social and political commentary among healthcare workers, patients, and policy-makers/directors provided further insight on general events. A common theme among interviews and focus groups was lack of *experiencia* (experience)—the general idea that physicians were not skilled enough due to lack of training or knowledge regarding dengue clinical management. Peripheral health centers and physicians were criticized for not having adequate preparation or familiarity with dengue management. One resident admitted to not having been properly trained on dengue management until he arrived at the pediatric hospital:

In the interior of the country doctors do not know how to manage dengue, they have not been well-trained. Before I arrived here I did not know how to manage a dengue patient. I attended few cases, but I did not give those cases the importance that dengue merits. It wasn’t laziness, I just did not know. The doctors in the interior must be trained so that they can manage dengue just like at higher-level centers because that [type of] management can be given almost anywhere…(Fourth Year Resident, 2016)

Other physicians in the focus groups shared similar sentiments. Residents in the pediatric hospital felt that they had better training only because they were lucky enough to be working at one of the most respected and academic hospitals in the country—something many doctors were not privileged with. Nonetheless, lacking experience (or training) was not always an acceptable excuse. Many government officials and doctors believed that the onus lied on physicians teaching themselves how to manage dengue properly. One of the Vice Ministers of the MSP commented on the matter:

First, [the MSP] assumes Dominican doctors should know endemic diseases very well. That is, there is no reason that a Dominican doctor does not know how to handle dengue because he sees dengue frequently. (MSP Vice Minister, 2016)
Since dengue fever is an endemic disease, doctors are expected to know how to manage and diagnose patients adequately. The responsibility often lies on the doctor to be auto-didactic when it comes to dengue fever care. There are dengue fever trainings and conferences available, but some physicians confessed to not having received training since medical school—for some that meant 3-4 years. Some admitted to attending exposiciones (conventions) and charlas (talks or presentations) on dengue, but that they weren’t actual trainings. Others said they were trained after the dengue guide was released. In September 2015, the MSP published and distributed the first edition of the Guide for Dengue Clinical Management. The guide provided an abridged, “on-the-go” reference to dengue management as described by WHO/PAHO that doctors were expected to learn and use. However, doctors’ previous medical training and experience provided barriers to following the guidebook. Some physicians felt that the guidebook was too broad and did not account for unique cases. Many physicians were faulted and criticized for not adhering to the management protocol. The following quotes highlight the latter:

It is important that I say this, I have had the opportunity to work in private institutions where the management for dengue patients can vary. For example, when there is a severe patient with one day of disease manifestation the case is consulted with another department, though it is not indicated under the [dengue case] management protocol. I do not know why [the private centers] do not adhere to what the guide says. For example, they consult with hematology because the platelets are very low and use medications that are not listed in the guide, but are satisfied that doctors from other countries use them even though it is not in our guide. (First Year Resident, 2016)

Yes, there are problems. For example, the fact that there is a clinical management guide where it is established how to handle the cases; this is law for all. We still have many establishments and many doctors who do not know that, or who know it but do not know how to act or refuse to act accordingly. This is what is producing many, many problems. (MSP Director, 2016)
There was an effort to update doctors on dengue management, especially following the outbreak. Conferences and trainings were held on an ongoing basis for months after the outbreak; the format and content of these were not investigated.

Dominican policymakers, practitioners, and patients acknowledged the country’s problem regarding dengue clinical management. Physician inexperience contributes to poor clinical management that leads to higher morbidity and mortality and affects surveillance data. For example, the DR’s CFR (a statistic calculated from a country’s surveillance data) is 1.54 (PAHO 2014)—the highest in the Americas region. This number is a consequence of poor clinical management and indicates high mortality among dengue fever patients in the DR. Thus, the DR is internationally and nationally recognized for having poor dengue management and high case fatality, yet a sustainable solution does not exist.

4.2 Hospital Level

4.2.1 Macro: Clinical Management

The high number of dengue deaths was partly due to a lack of proper clinical management. Hospitals were inundated with patients and many patients were transferred from peripheral centers to bigger, more recognized centers in the capital. Sometimes, during the transfers the patient would worsen. Patients would arrive at the referral center in critical condition. During an interview, the sub-director of one of the study hospitals commented on the matter:

..the epidemic was very aggressive. There were more than 115 dead. So many [patients] arrived here in the hospital, but (due to complaints) it isn’t that here
[we] don’t know how to treat dengue, the problem is the state and the conditions in which other centers send the patients. That is the problem and is partly the cause of mortality in [dengue] patients…(Sub-Director of Hospital, 2016)

Referral centers admitted many dengue patients during the outbreak, which caused crowding. Space became a limited resource along with time. Time was one of the most important factors in dengue management, which also affected sample collection for laboratory confirmation. The unprecedented number of deaths was blamed on time: transfer time, not capturing the case on time, and not beginning treatment on time.

Interview participants from the MSP acknowledged this problem:

We have another problem and that is in relation to the confirmation of severe dengue cases. Generally, we have a lot of difficulties when severe cases of dengue arrives because [patients] arrive in severe condition due to not having been diagnosed on time. Thus, samples are not taken before the patient worsens and then when they do get worse they [still] do not take samples…(MSP Director, 2016)

…early establishment of the treatment, that is one of the other big points of preventability, first contact. No matter where it is, if it is in a UNAP, a simple hospital, or a hospital of high complexity, the first that establishes contact with the patient is the one who must start treatment quickly: hydration. That would greatly avoid deaths. (MSP Director, 2016)

Untimely diagnosis, or health-seeking, increases the probability of patients developing severe dengue. Patient focus group participants also commented on dengue clinical management and told stories of the bad experiences they had at peripheral centers before seeking care within the referral hospital:

Every time I asked for the phone to talk to the doctor, the doctor would hang up. And when I arrived here a doctor told me that the [other] doctor wanted to kill my child. The [other] doctor had given her two medications where [my daughter] began to convulse. When that doctor saw that the child was talking incoherently she took off the child’s clothes, filled the bed with water, and put cotton under the armpits with alcohol. When the fever was really burning, she then sent [my daughter] over here by ambulance. And before making the decision to send my
child here, I saw that there were other children who vomited blood, and they were only glanced at as they got worse. (Mother, 2016)

She was admitted to another hospital, because she had contracted dengue for the first time (it has now been twice). I decided to come here because the first time they cured her at once, but she stayed in the hospital for 10 days and became swollen. [During that visit,] I told the doctor to give my daughter permission to come here and the doctor said no. That she would not assume responsibility, that she does not agree to that. [Now,] I want to go to that hospital to see that doctor because if my granddaughter had died...Then when the doctor saw that [my granddaughter] started vomiting and was swollen, that was when the doctor called an ambulance to bring her here, but it was there where the child got worse. (Grandmother, 2016)

Thus, bad experiences with clinical management at peripheral centers affected patient health-seeking and caused patient to distrust their local health centers—behaviors and feelings that negatively impacted timing of care.

Patients were not the only stakeholders concerned about clinical dengue care and management. Dengue is a delicate subject for many physicians due to the disease’s complexity. During my PO I gained a better understanding of the outbreak during which physicians noticed changes in disease manifestation that worried them. Instead of entering the critical phase on the fourth or fifth day of fever onset, patients were experiencing shock symptoms by the second day. This caused confusion and unease on a general level—a fear of dengue was created among the healthcare culture. Doctors began to primero pensar en dengue, or ‘first consider dengue,’ when presented with a febrile case. Febrile patients were managed as dengue until proven otherwise. Some physicians feared not capturing dengue on time, of managing the patient wrong, or of death.

Physicians had the following to say within FGs:
Last year dengue behaved very strangely from how it does usually. Each year it behaves in a different way as reported by infectious disease specialists. For example, the common thing is that they extravasate on the fifth day, but last year we saw extravasated patients on the second day. The average was between the 3-4th day and there were patients who were admitted without any warning signs. They extravasated in such an exuberant way that they had to be carried to intensive care, and that’s why we started to admit all patients suspected of dengue. (Second Year Resident, 2016)

The problem is if we confuse it, the patient will do well if I treat him as dengue, because what I'm afraid of is that the patient with dengue dies and dies fast. (Third Year Resident, 2016)

According to resident doctors and government officials participating in FGs and interviews, one cause of untimely diagnosis and management were doctors who did not assume the responsibility of dengue patients, due to fear. This lead to an increase with patient transfers and also influenced patient health seeking.

The fear of death was complex because physicians lamented the deaths and felt guilt, but there was also a political fear attached. A hospital’s reputation could be detrimentally affected by high case mortality, creating bad media and resulting in dismissal of respected directors and veteran doctors. Furthermore, the DR highly depends on the tourism for its economy, and bad media can negatively impact the tourist industry. Tourists are less inclined to travel to areas where dengue fever, or any infectious disease, has high transmission rates or outbreak occurrences. Thus, the fear of dengue goes beyond the healthcare sector and into the national sector since a country’s reputation is at stake.

4.2.2. Micro: Resources

Equipment, supplies, medications, and physicians are key health care resources. Missing or inadequate resources could have detrimental effects to patient care while
simultaneously impacting reporting and surveillance. Patients, physicians, and government officials all spoke about the lack of supplies and human resources within the health sector:

For example, there are many medical centers that, because of the volume of patients they have, do not have the time to admit all [dengue] cases. Sometimes, due to infrastructure problems, internet problems, communication problems, and a lack of epidemiologists in the medical center. Basically, that makes it impossible for them to report. (MSP Director, 2017)

SENASA covered my medications. But that night there was chaos, there were a lot of people in the emergency ward and the hospital had almost nothing. The hospital of [province] is nonsense. I had to buy everything. (Mother, 2016)

What happens is that patients are admitted with the diagnosis of probable dengue and the doctors stay with the patient perhaps without the conditions to have them there, without an infusion pump or without staff that is permanently attentive. (Fourth Year Resident, 2016)

It was clear there was a serious lack of health resources in the country. Physicians were particularly affected by this and commented on poor wages along with not having the necessary supplies to properly manage patients. A resident physician, on average, earns $660 USD a month and works 40-80 hours a week.

At the tertiary level, lack of coordination among health practitioners and patient surplus put stress on the physicians. Often times, physicians commented on having *mucho trabajo*, a lot of work. It was common for them to speak about patient surge and performing multiple jobs, from housekeeper to nurse. This was recognized among hospital residents, and at the local PAHO division; physicians were over-burdened:

Here you perform all kinds of roles, from R1 to R4. Just because someone has a blue nametag does not mean that one is an R3. For example, the emergency ward is always very congested and there is an R1, an R2, and an R3 but we do not suffice, so we have take on the responsibility of each [residency] year. Between injections, admitting patients, and writing orders you do everything here, because it's a lot of work. (Third Year Resident, 2016)
I think the most important limitation is that the human resource is saturated [with work]. (PAHO Consultant, 2017)

One reason for this is due to the scarcity of physician employment opportunities. Many physicians after finishing their last year of residency were left without jobs. Poor job prospects and wages, stressful work conditions, and lack of resources impact physician morale. When physicians are depleted of energy and supplies, dengue patient management and care suffers.

4.3 Community Level

4.3.1 Macro: Municipal Services

Various studies have found that community members associate dengue risk with inadequate municipal services (Stewart-Ibarra et al. 2014; Perez-Guerra et al. 2009; Perez-Guerra et al. 2005; San Martin and Prado 2004; Whiteford 1997). In this study, when family members were asked about dengue prevention, most mentioned lack of water supply and basic sanitation, suggesting that dengue fever could be better prevented if these services were improved. Focus group discussion among patients revealed that the same was (still) true in the DR. One focus group participant commented the following:

The garbage is only collected twice every 3-5 days. Trash attracts a lot of mosquitoes, mice, and cockroaches. Also, if there was [constant] water here in the DR we would not have a water storage problem. When storing water, in one week, larva always appear. For example, where I live, water comes on Tuesdays and Thursdays and sometimes not for a week. You must understand that a family of 7 people need to have a minimum of at least five tanks, along with jugs…Sometimes the water doesn’t come for two weeks. If they solved these problems those mosquitoes would disappear. [The mosquito] uses water and clean water, but we need to have water in the house; we have to bathe, we need water for everything. (Mother, 2016)
Local residents felt that dengue would not be a large public health burden if there were no need for water storage. Though water is a paid utility, many Dominicans must store water in their homes due to lack of a steady running supply. This has created a water storing culture. Households commonly have one or more 55-gallon tanks filled with water and/or tinacos (cylindrical water tanks with lids capable of holding 145 gallons to 1000 gallons of water). Some homes also have cisterns. These reservoirs serve as lifelines when pipeline water is unavailable. The water stored is used for bathing, washing clothes, washing dishes, and sometimes cooking, but if stored improperly often become ideal *Aedes aegypti* breeding habitat. Thousands of residents are affected by the lack of constant running water, meaning that thousands of water reservoirs exist. Thus, in the DR, there are thousands of potential breeding sources for *Aedes aegypti*—and all within or around the home where hosts reside.

Garbage collection is another paid service, which is not performed regularly. In general, municipal services are the responsibility of the *ayuntamiento* (city hall) of the municipality. Sometimes the *ayuntamientos* will work together with a sector’s *junta de vecinos* (community board) to help provide these services. Dominicans typically relate a garbage-free environment with low risk for disease transmission. The absence of garbage is related to cleanliness. The subject of cleanliness is delicate because there is a negative social stigma related to not keeping your environment or home clean (Stewart Ibarra et al. 2014). This belief is strong among Dominicans. It was common among all interviewees to put the onus on others to keep their houses and yards clean since mosquitoes were perceived to breed in the neighbor’s yard. Most attributed the problem to a lack of education. The following quotes from the FGs and interviews comment further:
For example, here there are families that are hygienic and others that are not. There are others that are disgusting and others that clean more than the Devil. There are times when a mosquito appears that isn’t even yours—it’s the neighbors! So, it’s a matter of education. (Mother, 2016)

If there isn’t adequate sanitation, then a problem exists regarding the final destination of solid waste. [If not properly disposed of], the waste can accumulate water and be converted into a criadero of mosquitoes. That has to be taken care of; we have to educate the public to maintain their environment and home clean. (MSP Vice Minister, 2016)

Thus, the cleanliness stigma was related to an individual’s education level, where residents felt that the less educated one was the more unclean, or dirty, they were. Not only was there a stigma related to being untidy, but it was also tied to the larger stigma of being poor and uneducated. The DPS, the Department of Health Promotion and Education (DIGPRES), and other departments of the MSP are responsible for community education and social mobilization to help in dengue prevention efforts. Nevertheless, these have not been effective in dissolving such stigmas. It is understood among the academic community that dengue fever is not a “disease of the poor;” however, these stigmas make it difficult for educational messages to positively influence perceptions, behavior and attitudes within communities. The task becomes more difficult when trying to achieve this at the national level.

4.3.2 Micro: Government Disregard

Despite national campaigns and local prevention and education efforts, practitioners and patients often commented on the lack of presence of the government. Some said that the government only becomes active during elections and when cases of dengue fever become too high. Others admitted that sometimes the government
fumigates, but that that doesn’t help. Several FG participants simply said that the government no hace nada (doesn’t do anything). One resident doctor had this to comment:

I notice that in other countries there are campaigns [against mosquitoes]. Here [the government] fumigates when they’re afraid of a dengue outbreak. Before that, all the mosquitoes are biting every one. There [the government] does nothing, but when people start to die you see [their presence]. (First Year Resident, 2016)

Her comment resonated with others. Many participants mentioned that the government only becomes active in dengue prevention and control when there is an outbreak or when “está de moda” (it’s a trending topic). Educational messages focused on dengue prevention and control measures also lack presence in the media and within communities. Many community members felt that they were not properly informed of dengue fever or other diseases. There was a belief that the government was not doing an adequate job of educating the public, especially through media campaigns. One FG participant expressed his sentiments on the matter:

The people that manage the information do not keep citizens well informed. They usually manage the information internally, where one, as a parent, feels powerless up to a certain point. One doesn’t know anything about [dengue] disease up to a certain point, unless one has studied medicine. One sometimes feels unprotected. (Father, 2016)

The absence of educational messages and information left local residents feeling both uninformed and unprotected.

The disintegrated relationship between the government and the community seemed further deteriorated by the belief that the government is corrupt. Participants believed that the government lied, stole, and cheated the community sector. Even
government officials were aware of this phenomenon. The following quotes, selected from the patient focus groups and policymaker interviews, highlight the disbelief and distrust toward the government among local residents:

Here everyone is bought, even the journalists. If you send a letter to the President, it never arrives. They say this is the poorest country, but it isn’t like that. It’s just that it’s badly managed. I want you to see how the politicians carry themselves around the country! Not even the President of the United States has more money than a politician in this country, and sadly they are all corrupt. (Mother, 2016)

Yes, the education level of the people makes them sometimes not believe that a mosquito causes dengue. They say, ‘That doesn’t matter, it isn’t true [that a mosquito causes Zika, dengue and chikungunya]. Those are matters of the government so that the people become scared.’ (MSP Director, 2016)

What happened was that in a given moment the MSP lost credibility, in other words the public did not believe in what the MSP said... (PAHO Consultant, 2017)

It was clear that the community did not trust the government; many felt abandoned. One mother captured the overall sentiment in one phrase: “nosotros somos huérfanos de la autoridad” or “we have been orphaned by the authorities.”

In order for dengue policy and interventions to be effectively implemented and sustained, community-government relationships must be improved. If local residents do not confide in their national government, or disregard their efforts, then dengue intervention success is unlikely.
Chapter 5

Discussion

What is missing from much of the research on mitigating the dengue disease burden is a holistic approach involving these stakeholders, each of which is ultimately affected by and has a role in disease transmission, morbidity and mortality. Issues related to dengue care, management, and prevention were revealed through semi-structured interviews, focus groups and participant observation with the three groups of actors within the health care system: patients, practitioners and policy-makers. Each group gave their views on perceived barriers to dengue fever clinical diagnosis, management, and prevention and control that highlighted local social and political identities, such as who is ultimately responsible for proper dengue care. Requesting simple solutions to vector-borne disease control undermines the complexity of disease transmission that indisputably involves human actors and their environment, which includes associated perceptions, beliefs, knowledge, behaviors, and the policies that guide each.

This study’s findings help advance knowledge on the sociocultural and political accounts of dengue fever realities and concerns among three groups of key stakeholders in the DR: patients, practitioners and policy-makers. These perceptions are related to the diagnostic-management-surveillance scheme and provide culturally and locally significant knowledge that can be used to inform dengue related policy-change and interventions. Improved policy and interventions positively affect dengue healthcare and diagnostics and enhance national surveillance systems. This results in better outbreak response and more efficient prevention and vector control. In this framework, success cannot be achieved without understanding local realities to inform policy, and fostering
integrated collaboration to implement and sustain changes toward dengue fever burden reduction.

The unprecedented dengue death toll of the 2015 outbreak highlights weaknesses of the DR’s health system and opportunities for improvement. After the outbreak, the Dominican government led the national cleanup campaigns to reduce *criaderos* and the MSP changed its policy to require all cases of dengue deaths to be serologically confirmed and established the Dengue Team to audit the unconfirmed deaths. These efforts are not enough for sustainable dengue fever mitigation efforts. The Dengue Guide was released shortly after the outbreak, which was not timely enough for those already deceased or diseased. Much onus is placed on the Dominican doctor to know how to diagnose and manage dengue; doctors are expected to teach themselves. A doctor is as responsible for self-actualizing in dengue management as the government is in self-actualizing its surveillance, control and prevention efforts. Both have direct consequences on the health of the nation’s citizens, which in turn have a direct consequence on the nation. Additionally, DIGEPI reported deaths that were not laboratory confirmed and stopped in order to confirm them. This caused a distortion of information among the media and distrust in the MSP. Once the dengue deaths were audited issues with clinical management and diagnosis were found.

A barrier to proper dengue diagnosis and management was physician inexperience. Government officials and physicians perceived that practitioners were ill prepared to manage the disease and not adequately following the Dengue Clinical Management Guide that was provided to them. This meant dengue fever cases were not being managed efficiently. Many cases in peripheral centers were transferred to larger
referral centers, where, upon transfer, the patient’s condition would often worsen. Patients also described having experienced poor attention within peripheral centers. Among physicians, dengue was a worrisome event leading to a diagnostic bias where they would first consider dengue as the diagnosis until proven otherwise. Many doctors felt over-worked, and both policy-makers and physicians acknowledged a wide fear of dengue. Physicians were afraid of not diagnosing and managing dengue cases on time and of patient death. Both practitioners and patients commented on the lack of medical equipment, supplies, and medications available, especially within peripheral centers, which did not provide acceptable conditions for case management.

Community members associated the risk of dengue with inadequate municipal services. An unsteady water supply meant households required storing water in tanks that served as criaderos. Garbage pick-up and the subject of cleanliness were related to disease transmission. A negative social stigma was tied to being unclean, placing responsibility on individual households to keep their homes clutter and waste free. Those who did not were perceived to create breeding habitats for mosquitoes and considered uneducated. The community also felt abandoned by government authorities, claiming that the government “no hace nada” or “doesn’t do anything” in relation to dengue prevention and control. Community members felt the government managed information internally and was corrupt, consequently creating a feeling of impotence among community members.

Many of these themes coincide with dengue studies conducted in the DR in the 1990s. Coreil et al.’s household ecology of disease described how water storage practices were a large function of dengue disease transmission in a Dominican barrio, or
neighborhood (2000). A modification of water storage practices would require a more consistent supply of water (Coreil et al. 2000), but this change would need to come from the policy arena. The ethnoecology of dengue fever described Dominican citizen’s negative sentiments toward their government, claiming there was a mala-union, or bad union, amongst them (Whiteford 1997; 2000). Dominicans felt the government did not help, and families felt their efforts toward prevention were futile (Whiteford 1997). Twenty years later, these key social and political realities in the DR are still salient.

Though the themes identified in this study pertain to the DR case, some of them are consistent with findings from other studies in the dengue field. For example, Tomashek et al. (2014) reported a lack of physician knowledge of proper dengue case management in Puerto Rico where dengue fever is also endemic. The study concluded that for over 40 years, dengue diagnosis and clinical management was “not optimal” there. Lack of physician knowledge, along with lack of medical supplies, equipment and staff greatly contribute to the clinical dearth of proper management in the DR and other affected countries. Khun and Manderson (2007) mentioned a shortage of medical supplies and equipment within local health centers affected patient health-seeking behaviors in Cambodia. Similarly, patients in the DR were either transferred or chose to seek care at tertiary levels due to the lack of resources within peripheral health centers. In communities, problems with inadequate municipal services are believed to be associated with dengue transmission (Whiteford 1997, 2000; Coreil et al. 2000; Spiegel et al. 2005; Pérez-Guerra et al. 2005), where the theme of cleanliness is also an important factor in reducing dengue fever risk (Gomez-Dantes and Willoquet 2009; Pérez-Guerra et al. 2009; Stewart Ibarra et al. 2014). In Ecuador, it was found that broadly addressing
Dengue fever control as part of municipal sanitation resulted in a successful campaign (Stewart-Ibarra et al. 2014). Stewart Ibarra et al. (2014) also reported community members in Ecuador feeling neglected and powerless with little political access. Themes of which are common among the lower socio-economic classes of many dengue-endemic, developing nations.

The themes revealed in this study can provide new perspectives to inform community members, health practitioners, policy-makers and researchers of ways to strengthen dengue surveillance and management protocols and develop trust within the healthcare system to foster fluid and sustainable collaboration among all stakeholders. Basic sanitation and water supply services must continue to improve. While this is an ongoing effort, the government can further aid the ayuntamientos by requiring certain goals be met, allocating more funds, and re-framing messages. Current messages aimed at dengue prevention and control in the DR focus more on water storage and water accumulation. Increasing the emphasis on waste management would help significantly too. The government should be careful to not propagate stigmas associated with unclean and untidy home environments. Previous work has shown that a negative stigma is tied to poverty and uncleanness in association with dengue (Steward-Ibarra et al. 2014), and such stigma exists in the DR. Campaign messages must avoid further marginalizing the poor or make judgments based on clutter, waste, and debris accumulation in and around homes. A higher priority should be placed on achieving constant access to water in urban areas. Within the DR’s two largest cities, Santo Domingo and Santiago—also the two cities with the highest incidence of dengue fever—there are thousands of citizens without continuous water supply. This means there are many breeding opportunities for
mosquitoes due to high water storage practices. The government needs to respond to this key, underlying issue if it hopes to reduce dengue fever transmission.

Increased government involvement and educational messages would improve government-community relationships. Active presence of government in communities will help to re-build trust and dissolve feelings of neglect and impotence among community members. The government is the prime leadership role; therefore, it should inherently strive to provide the finest example and lesson: inspiring and motivating by being the model others seek. If a democratic nation’s citizens do not believe in their government, then the democracy is an illusion. Many in the DR believe the government to be corrupted. To help change the minds of her citizens, the DR must choose transparency. A PAHO consultant suggested using transparency as a way to mend the perception the citizenry has of its government; report the truth. Though the consultant was talking about reporting dengue deaths, her suggestion has a broader overtone, implying that honesty is generally the best way to win back the people.

Continued physician training should be prioritized within hospitals. Runge-Razinger et al. (2016) emphasized the importance of having health professionals trained in dengue diagnosis and management, and suggested hands-on training during rounds and case conferences. In the DR, Badurdeen et al. (2013) reported that improved training of local health staff and civil servants was recommended for better outbreak response. As a dengue-endemic country, the federal government should mandate and standardize yearly dengue workshops that all public health workers must attend within their respective, or nearby, provinces. These workshops could include information on the dengue viruses, vaccines, updates on diagnoses and management schemes, case discussions, prevention
and control efforts, and the progress the nation has made in each. Workshops would last
depending on the material covered and would be organized by the top dengue experts in
the DR and neighboring countries. Additionally, to help with reporting and case
management, it should be required for all hospitals of secondary and tertiary nature to
have a Dengue Clinical Management Team. These physicians would carry the
responsibility of managing all dengue fever cases within the hospital: ambulatory,
admitted, and emergency/critical. They would also be accountable for reporting on
SINAVE to control for under-reporting, or over-reporting during outbreaks. The team
would also help ensure that all admitted and emergency dengue patients, on their 5th or
6th day, have samples taken for laboratory confirmation. Last, the team would evaluate
physicians on their dengue management and report to the Dengue Team within the MSP.
The hospital team should be comprised of at least 3 members in tertiary level hospitals,
and 2 in secondary: an epidemiologist (for reporting), and at least one doctor from
infectious disease and one from internal medicine. Pediatric hospitals would have no less
than 4 members to account for the pediatric specialty. While resident doctors would be
allowed to be part of the team, the head specialists cannot be residents and must be
present in the hospital with residents at all times, helping ease workload for some
physicians.

Improved policy, coordination, and transparency are necessary for the DR to
achieve successful dengue surveillance. Decentralization of central power works well if
all decentralized bodies are coordinated while keeping individual autonomy. To further
assist with coordinated efforts, prevention and control should be managed by one MSP
branch: CENCET. Since the outbreak, CENCET’s efforts have been mainly concentrated
on malaria. Other sectors of the government, such as the army and public works, have organized their own vector control teams. These teams do not use the same machines or insecticides as CENCET. It is unsure what the effects of these fumigations are, both in terms of effectiveness and of unwanted side effects. CENCET is required to only use chemicals that have been certified and tested. They also conduct field tests of the products themselves. Investing more in CENCET to act as the main governing branch for vector control will ensure environmentally and biologically safe agents for field use. CENCET does not have the financial resources or human resources to physically aid the entire country in all prevention and control efforts. However, they can serve as the directing body. Their office should be moved to a more centralized location near the main MSP branch for better coordination. CENCET’s entomologists and team can train, monitor, and evaluate the decentralized teams. Some at MSP did want to move in this direction. The DPS are already responsible for prevention and control in the provinces. There is also mention about employing a technically trained entomologist at each DPS. Within the DPS, the entomologist would coordinate control efforts with local technicians, trained by CENCET. The entomologist would also organize and help conduct the entomological surveys, ensuring CENCET receives all data in a timely matter. This would help increase control efforts in each province and will help in maintaining prevention efforts routine by supporting community social mobilization efforts already in place by the DPS and DIGPRES. Additionally, increased visibility of government workers will help the MSP recover and retain the confidence of communities.
5.1 Study Limitations

Several factors limit the broad generalization of this study’s findings. This study was cross-sectional and conducted immediately after a dengue outbreak that resulted in a high death toll. Dengue fever was thus part of the national discourse for months, and persisted throughout the Zika outbreak that closely followed beginning in January 2016. Immediate policy changes occurred affecting healthcare delivery at the national and community levels, changes that were not part of normal, pre-outbreak health activity in the DR. Thus, the resulting themes generated in this study could be partly attributed to dengue fever’s high profile at the time. Additionally, the small sample size did not permit statistical tests of the differences in responses between groups or the use of other quantitative analytical techniques.
Chapter 6

Conclusions

This updated account of experiences in the DR can be used in policy and decision-making schemes aimed at dengue disease mitigation. Disease eradication efforts require national and local policy changes along with honest, organized, and unbreakable inter-sectoral coordination. One of the most important limiting resources, especially within developing countries, is healthcare funding. National government spending in these countries is not enough for sustained efforts. Fortunately, NGOs and private institutions are available to help a nation that prioritizes the health of its people and provides a plan of management. The DR can help itself by showing true commitment to reducing the burden of dengue fever with new dengue policy implementation, improved coordination and training between and among the government and its healthcare branches, and by promoting transparency in reporting dengue fever news, statistics, and educational information to its citizens. Authentic efforts lead to change.

The case of the DR also is an example of inadequate vector control coverage and implementation, a problem that is not specific to that nation (Runge-Razinger 2016). The WHO IVM strategy can be adapted to fit local realities, instead of taking highly systemic approaches to control. If the strategy accounted for the current sociocultural and political realities that influence attitudes and behaviors, interventions and policy-changes can be made to ensure effective program implementation and sustainable adherence to protocol. This is especially important now that vector control is necessary to target all illnesses transmitted by *Aedes spp.*, including dengue, Zika, and chikungunya, yellow fever, and several forms of viral encephalitis. These are small steps that can lead to sustainable
improvements in surveillance and case management of arbovirus infections in the DR and other dengue-endemic countries.
Bibliography


PAHO, *Number of Reported Cases of Dengue and Severe Dengue (SD) in the Americas by Country*, Annual Case Report, 2016


Appendix A: Verbal Consent Forms

Patient Verbal Consent Script:

VERBAL CONSENT SCRIPT

Diagnosing Dengue: The Utility of Oral Fluid Specimens
Focus Group: Patients

Hi, my name is Deborah and I am the study coordinator working with the University of Miami and (hospital).

PURPOSE OF STUDY:

We have invited you to take part in this research study because we are trying to learn more about the community’s thoughts on dengue fever and health care. You will be asked to share your thoughts and opinions freely and respectfully within the group. If at any time you do not feel comfortable answering a question, you may choose not to; you may also choose to leave at your discretion. There will be no consequences for doing so.

We are also requesting your permission to make an audio-recording of the session, so that we may review the conversations and make more detailed notes for the study. All names, places, and other personal information will be deleted from the audio recordings and notes, with all information remaining strictly anonymous and confidential. All of your answers will be anonymized by using a special identifying number in place of your name. All of the papers pertaining to the study will be kept in a locked file cabinet, and all electronic data will be stored and backed up in encrypted computer files. Only people who are directly involved with the project will have access to the original records. When the project is completed, no individual will be identifiable in any way. All participants will have the right to review the audio recordings if desired.

There are no direct benefits for participating in this focus group. The information acquired today will be used to learn more about dengue fever in the community, and for educational purposes. The transcripts of this focus group will not be used for any other purposes. You will not receive payment or compensation for being part of this focus group, but we have provided refreshments to make the session more enjoyable, and to thank you for your time.

Your participation is voluntary. You can decline to participate, and you can stop your participation at any time, if you wish to do so. By participating in the focus group, this means you consent to participate in this research project. Does anyone have any questions? Is everyone still comfortable participating in the focus group as I have just described? [PAUSE FOR CONSENT; GIVE PEOPLE CHANCE TO GO.]

If you have any questions or concerns about the research, please feel free to contact Justin Stoler (305-284-6692) and/or me, Deborah Roque (786-281-3931). If you have questions regarding your rights as a research participant, contact the University of Miami, Human Subject Research Office at (305) 243-3195.
Practitioner Verbal Consent Script:

VERBAL CONSENT SCRIPT

Diagnosing Dengue: The Utility of Oral Fluid Specimens
Focus Group (or Verbal Questionnaire): Practitioners

Hi, my name is Deborah and I am the study coordinator working with the University of Miami and (name of hospital).

PURPOSE OF STUDY:

We have invited you to take part in this research study because we are trying to learn more about health professional’s thoughts on dengue management and reporting within hospitals. You will be asked to share your thoughts and opinions freely and respectfully within the group (or questionnaire). If at any time you do not feel comfortable answering a question, you may choose not to; you may also choose to leave at your discretion. There will be no consequences for doing so.

We are also requesting your permission to make an audio-recording of the session, so that we may review the conversations and make more detailed notes for the study (will only be required for focus groups; questionnaires will not be recorded). All names, places, and other personal information will be deleted from the audio-recordings and notes, with all information remaining strictly anonymous and confidential. All of your answers will be anonymized by using a special identifying number in place of your name. All of the papers pertaining to the study will be kept in a locked file cabinet, and all electronic data will be stored and backed up in encrypted computer files. Only people who are directly involved with the project will have access to the original records. When the project is completed, no individual will be identifiable in any way. All participants will have the right to review the audio recordings if desired.

There are no direct benefits for participating in this focus group (or questionnaire). The information acquired today will be used to better understand dengue management and reporting within the Dominican health care system. The transcripts of this focus group (or the data of this questionnaire) will not be used for any other purposes. You will not receive payment or compensation for being part of this study. We have provided refreshments to make the session more enjoyable, and to thank you for your time (will only be provided for focus groups).

Your participation is voluntary. You can decline to participate, and you can stop your participation at any time, if you wish to do so. By participating in the focus group (or questionnaire), this means you consent to participate in this research project. Does anyone (Do you) have any questions? Is everyone (Are you) still comfortable participating in the focus group (or questionnaire) as I have just described? [PAUSE FOR CONSENT; GIVE PEOPLE CHANCE TO GO.]

If you have any questions or concerns about the research, please feel free to contact Justin Stoler (305-284-6692) and/or me, Deborah Roque, (786-281-3931) or (829) 854-1027. If you have questions regarding your rights as a research participant, contact the University of Miami, Human Subject Research Office at (305) 243-3195.
Appendix B: Data Tables

Table 1: Descriptive characteristics of patient FG sessions

<table>
<thead>
<tr>
<th>FG</th>
<th>Number of Participants</th>
<th>Gender</th>
<th>Representative Barrios</th>
<th>Recruitment Method</th>
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<td>7</td>
<td>1 M 6 F</td>
<td>Barahona, Baní, Santo Domingo: Los Alcarrizos, Zona Oriental</td>
<td>Convenience Sampling</td>
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<tr>
<td>2</td>
<td>8</td>
<td>8 F</td>
<td>San Pedro de Macoris, Santo Domingo: Herrera, Villa Mella, Pedro Brand</td>
<td>Convenience Sampling</td>
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<tr>
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<td>10</td>
<td>10 F</td>
<td>Barahona, Monte Plata, Santo Domingo: Villa Mella, San Luis, Cristo Rey</td>
<td>Convenience Sampling</td>
</tr>
<tr>
<td>4</td>
<td>11</td>
<td>11 F</td>
<td>Barahona, Moca, Higuey, Azua, Bávaro, Santo Domingo: Pedro Brand, Pantoja</td>
<td>Convenience Sampling</td>
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Table 2: Descriptive characteristics of practitioner FG sessions

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<tr>
<td>2</td>
<td>12</td>
<td>1 M 11 F</td>
<td>Second Year</td>
<td>Convenience Sampling</td>
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<td>3</td>
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<td>1 M 7 F</td>
<td>Third Year</td>
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<td>3 M 5 F</td>
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Table 3: Descriptive characteristics of policy-maker interviews

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Appendix C: Patient Focus Group Script

Focus Group Moderator Guide: Community

Red Text: Spoken by interviewer

[After reading verbal consent] Ok, if there are no more questions, let’s begin talking about general human health issues in the community.

1. What do you all feel are the biggest health concerns in the community?
   o Follow up (if dengue is not mentioned): What about dengue fever?
   o Goal: Top (5) health concerns. Try to get everyone to agree. See where dengue fits

2. Tell me more about the government and their role in health care.
   o Follow up: Are there workers in the community from the government? What are their relationships with the community? [If mala union is mentioned, continue to ask about it]
   o Goal: List what the community thinks about the government and the government’s role in health. Understand this specifically with dengue.

Now we’re going to focus specifically on dengue fever.

3. When are you most worried about dengue?
   o Follow up: Is there a fear of contracting dengue in the community? Why or why not?
   o Goal: List top 3-4 reasons. See if risk or fear comes up (community may or may not fear contracting dengue)

4. What do you feel your risk is of contracting dengue? Why?
   o Goal: List top 3-4 reasons of why feel low or high level of risk

5. Who do you feel is responsible for dengue fever prevention? [Distinguish between should be responsible vs can be responsible]
   o Follow-up: Has the community made any efforts in practicing dengue prevention (ie. source reduction, educational outreach)?
   o Follow-up: Do you think the community can come together to do so and keep it sustainable? Why or why not? [If “mala union” comes up, continue to pursue it]
   o Goal: Try to distinguish roles of government (MOH), mosquito control, community, individual, together with barriers to action. Try to find consensus

6. Please describe the relationship between the MSP and the community.
   o Follow-up: Do tensions exist? How and among who?
   o Follow up: Do you think these tensions affect the dengue control and prevention efforts? How?
   o Goal: If tension do not exist, then determine other reason for stressed community-government relationships
This is really enlightening. I want to take a step back and talk about how you are dealing with this illness at home.

7. Typically, how does one treat dengue fever?
   o Follow up: What do you use and why do you choose to treat this way?
   o Follow up: When do you decide to seek outside care?
   o Follow up: Who do you go to? How do you decide whom to go to? [if no one answers with “traditional healer, brujo, or curandero” then ask next probing question.]
   o Follow up: What about “curanderos” or “brujos”? Do people still seek health advice from these? [if not sought, then continue with next question] If so, can you tell me a few examples of some typical advice, from them, for dengue treatment?
   o Goal: List 3-4 common remedies and/or practices. List 3-4 situations when seeking outside care is needed. List 3-4 reasons people use in deciding whom to go to for care.
   o Goal 2: If traditional healers aren’t sought, or do not really exist, then focus on self-treatment

8. What are your thoughts on how doctors and nurses treat dengue?
   o Follow-up: Does this affect your decision to seek care in hospitals or clinics?
   o Follow-up: What needs to change in order for you to seek care first at a hospital or clinic?
   o Goal: List 3-4 reason why trusted or not trusted. List 3-4 suggestions and rank which ones needed most for change. [Distinguish between trust and cost of systems. Pursue both. Trusting doctors and nurses and then trusting their management of dengue may be two different things. Tease out. See if answers imply sense of loyalty to certain hospitals or doctors]
   o Closing: Any other final thoughts or suggestions?

I am going to honor my promise of keeping the discussion within an hour and a half, and bring this session to a close. Are there any other questions? [TRY TO LIMIT TO ~5 MIN].

The information gathered today will be used by the University of Miami and ________ to better understand your community’s concerns about dengue and health. Thank you so much for joining me today and best wishes on the remainder of your day.
Appendix D: Practitioner Focus Groups Script

Focus Group Moderator Guide: Practitioners

Red text: what interviewer will speak

[After reading verbal consent] Ok, if there are no more questions, let’s begin talking about dengue diagnosis.

Dengue diagnosis:

1. Please explain how a patient is diagnosed with dengue.
   - Follow up: Please tell me what is the case definition used. [must know the definition yourself]
   - Follow up: When are patients admitted for care?
   - Follow up: Does this change during an outbreak? If so, how?
   - Follow up: What would you say are the barriers to accurately diagnosing a patient? What about for timely diagnosis?
   - Goal: Determine what case definition used (ie. PAHO), understand screening and admittance protocol for specific hospital, identify top barriers to accurate and timely diagnosis

2. How long does it usually take to diagnose a patient with dengue?
   - Follow up: Does this still hold true during an outbreak? If not, what changes and how?
   - Goal: Determine the differences, if any, in diagnostic protocols during outbreak and non-outbreak periods

3. How are dengue cases confirmed within the hospital?
   - Follow up: How long does it take for results to return? And how long does it take for the patient to receive the results?
   - Follow up: On average, how many patients are diagnosed with dengue during high transmission seasons/outbreaks? What about during low transmission?
   - Follow-up: Do outbreak periods and non-outbreak periods impact how you diagnose and treat your patients? If so, how?
   - Goal: Determine what tests are used to confirm dengue, and how long results take to return to both practitioners and patients. Determine whether number of confirmed cases differs during outbreak and non-outbreak periods, and whether protocol for dengue confirmation differs as well.

Now we’re going to focus specifically on dengue reporting.

4. Can you please explain the reporting process within the hospital?
   - Follow up: Who is responsible for reporting dengue? Are they also responsible for sending the reports out? If not, then who is?
Follow up: Do you know what happens after dengue is reported to the MSP (DIGEPI)?

Follow up: What do you think the percentage of confirmed cases that are reported is for this hospital?

Goal: Learn the reporting process within the hospital: who reports, who sends the reports, where are the reports sent, how often dengue is reported, how long it takes to send reports, and if the agency reports are sent to communicate statistics back to the hospital

5. Do reporting procedures differ during non-outbreak and outbreak periods? If so, how?

Follow up: Do you feel it is important to report dengue during non-outbreak periods? Why or why not?

Follow up: What are some barriers to reporting all dengue cases during outbreak periods? During non-outbreak periods?

Goal: Understand perspectives on reporting during outbreak and non-outbreak periods. List 3-4 barriers to reporting cases during outbreak and non-outbreak periods.

Suggestions:

6. How would you better enforce and ensure the reporting of dengue during both outbreak and non-outbreak periods?

Goal: List and rank suggestions to improve on reporting during outbreak and non-outbreak periods.

7. How would you improve the time of diagnosis and treatment for dengue patients during outbreak periods? What about non-outbreak periods?

Goal: List and rank suggestions to improve on diagnosis and treatment during outbreak and non-outbreak periods.

I am going to honor my promise of keeping the discussion within an hour and a half, and bring this session to a close. Are there any other questions? [TRY TO LIMIT TO ~5 MIN].

The information gathered today will be used by the University of Miami and ________ to evaluate health care professional’s concerns for the improvement of dengue surveillance, management and care. Thank you so much for joining me today and best wishes on the remainder of your day.
Appendix E: Practitioner Questionnaire (Structured Interview)

Diagnosing Dengue: The Utility of Oral Fluid Specimens

HELLO, HOW ARE YOU? (WAIT FOR RESPONSE) MY NAME IS DEBORAH AND I AM THE STUDY COORDINATOR. I WORK WITH THE UNIVERSITY OF MIAMI TOGETHER WITH (Hospital Name). THANK YOU FOR AGREEING TO PARTICIPATE IN THIS STUDY. IF YOU DON’T MIND, I’D LIKE TO ASK YOU A FEW QUESTIONS ON DENGUE AND YOUR WORK AT THE HOSPITAL. IS IT OKAY TO BEGIN? (WAIT FOR RESPONSE. BEGIN IF GIVEN THE OKAY.) THANK YOU.

Employment Information:

1. [OBSERVED] Patient’s gender:
   [ ] Male   [ ] Female

2. What is your position? Single select
   [ ] Doctor   [ ] Registered Nurse   [ ] Nurse Practitioner
   [ ] Lab Technician   [ ] Lab Assistant   [ ] Lab Manager
   [ ] Other _________________________

3. What is your specialty? Single select
   [ ] Infectious Diseases   [ ] Dengue   [ ] Pediatrics
   [ ] Lab Diagnostics   [ ] Internal Medicine   [ ] Other
   _________________________

4. How many years have you been practicing?

Dengue Training:

5. Were you trained for dengue clinical diagnosis in medical school?
   [ ] Yes   [ ] No   [ ] Not sure

6. Were you trained for dengue clinical management in medical school?
   [ ] Yes   [ ] No   [ ] Not sure

7. How often do you see dengue patients in your practice? [PLEASE ANSWER WITH ‘ALWAYS, ALMOST ALWAYS, SOMETIMES, ALMOST NEVER, OR NEVER’]
   [ ] Always   [ ] Almost Always   [ ] Sometimes   [ ] Almost Never
   [ ] Never

8. What dengue protocol does the hospital follow? Single select
   [ ] W.H.O   [ ] C.D.C.   [ ] Ministry of Health   [ ] Hospital’s
   [ ] Not sure   [ ] None   [ ] Other _________________________
9. Has the hospital hosted or offered formal trainings on dengue fever?  
[  ] Yes  [  ] No  [  ] Not sure

10. When was the last training?

11. You feel these trainings are helpful: [PLEASE ANSWER WITH ‘ALWAYS, ALMOST ALWAYS, SOMETIMES, ALMOST NEVER, OR NEVER’]  
[  ] Always  [  ] Almost Always  [  ] Sometimes  [  ] Almost Never  [  ] Never

12. If a formal training session about dengue clinical management and diagnosis were offered, would you attend?  
[  ] Yes  [  ] No  [  ] Not sure

[  ] I am too busy  [  ] I am not interested  [  ] Trainings aren’t helpful  [  ] I would like to learn more  [  ] Professional development  [  ] Add to my CV/resume  [  ] I would like know if I am doing it right  [  ] I have a day off  [  ] Other ___________________

[  ] IgM ELISA  [  ] IgG ELISA  [  ] NS-1 ELISA  [  ] PCR  [  ] Standard Rapid Dengue IgM Test  [  ] Not sure  [  ] Do not order tests  [  ] Other ___________________

Dengue Diagnosis:

15. What criteria do you use to hospitalize dengue patients? [CHECK ALL THAT APPLY] Multi-select  
[  ] Fever  [  ] Headache  [  ] Retro-orbital pain  [  ] Joint pain  [  ] Muscle pain  [  ] Severe abdominal pain  [  ] Persistent vomiting  [  ] Fluid accumulation  [  ] Mucosal bleeding  [  ] Lethargy  [  ] Shock  [  ] Liver enlargement  [  ] Respiratory distress  [  ] Severe bleeding  [  ] Severe organ impairment  [  ] Impaired consciousness  [  ] Platelet count  [  ] Hematocrit  [  ] Lab results  [  ] Other ___________________

FOR THE NEXT TWO QUESTIONS, PLEASE ANSWER WITH ‘ALWAYS, ALMOST ALWAYS, SOMETIMES, ALMOST NEVER, OR NEVER’. Single select

16. You send confirmatory bloodwork to laboratory for dengue:  
[  ] Always  [  ] Almost Always  [  ] Sometimes  [  ] Almost Never  [  ] Never
17. The laboratory results take too long to come back:
   [ ] Always   [ ] Almost Always   [ ] Sometimes   [ ] Almost Never   [ ] Never

18. How does the laboratory usually communicate the results? **Single select**
   [ ] E-mail   [ ] Leaves paperwork in work mailbox   [ ] Telephone
   [ ] Uploaded to secured system   [ ] Other _______________________

   PLEASE ANSWER THE FOLLOWING QUESTIONS WITH ‘ALWAYS, ALMOST ALWAYS, SOMETIMES, ALMOST NEVER, OR NEVER’

**Single select**

19. Test results are timely for clinical management:
   [ ] Always   [ ] Almost Always   [ ] Sometimes   [ ] Almost Never   [ ] Never

20. Communication between doctors and the lab is consistent:
   [ ] Always   [ ] Almost Always   [ ] Sometimes   [ ] Almost Never   [ ] Never

21. The laboratory results are reliable:
   [ ] Always   [ ] Almost Always   [ ] Sometimes   [ ] Almost Never   [ ] Never

22. Before final diagnosis, you wait for laboratory input:
   [ ] Always   [ ] Almost Always   [ ] Sometimes   [ ] Almost Never   [ ] Never

23. The hospital has enough clinical capacity for dengue outbreak response:
   [ ] Always   [ ] Almost Always   [ ] Sometimes   [ ] Almost Never   [ ] Never

24. During periods of peak transmission and outbreaks, the hospital manages dengue patients efficiently:
   [ ] Always   [ ] Almost Always   [ ] Sometimes   [ ] Almost Never   [ ] Never

**THANK YOU SO FAR FOR YOUR PATIENCE AND COOPERATION. I’D LIKE TO FINISH THE SURVEY WITH A FEW MORE QUESTIONS ON DENGUE REPORTING.**

**Dengue Reporting:**

PLEASE ANSWER THE FOLLOWING QUESTIONS WITH ‘ALWAYS, ALMOST ALWAYS, SOMETIMES, ALMOST NEVER, OR NEVER’

25. It is required to report dengue fever cases:
   [ ] Always   [ ] Almost Always   [ ] Sometimes   [ ] Almost Never   [ ] Never
26. Reporting dengue cases to the Ministry of Health or other government body is important:
   - [ ] Always
   - [ ] Almost Always
   - [ ] Sometimes
   - [ ] Almost Never
   - [ ] Never

27. Hospital management enforces dengue case reporting during periods of low transmission:
   - [ ] Always
   - [ ] Almost Always
   - [ ] Sometimes
   - [ ] Almost Never
   - [ ] Never

28. Hospital management enforces dengue case reporting during periods of peak transmission:
   - [ ] Always
   - [ ] Almost Always
   - [ ] Sometimes
   - [ ] Almost Never
   - [ ] Never

29. Hospital management enforces dengue case reporting during outbreaks:
   - [ ] Always
   - [ ] Almost Always
   - [ ] Sometimes
   - [ ] Almost Never
   - [ ] Never

30. Do you know how to report dengue fever?
   - [ ] Yes
   - [ ] No
   - [ ] Not sure

PLEASE ANSWER THE FOLLOWING QUESTIONS WITH ‘ALWAYS, ALMOST ALWAYS, SOMETIMES, ALMOST NEVER, OR NEVER’

How often do:

31. You report dengue cases during periods of low transmission:
   - [ ] Always
   - [ ] Almost Always
   - [ ] Sometimes
   - [ ] Almost Never
   - [ ] Never

32. You report dengue cases during periods of peak transmission:
   - [ ] Always
   - [ ] Almost Always
   - [ ] Sometimes
   - [ ] Almost Never
   - [ ] Never

33. You report dengue cases during outbreaks:
   - [ ] Always
   - [ ] Almost Always
   - [ ] Sometimes
   - [ ] Almost Never
   - [ ] Never

34. Dengue cases in Santo Domingo are generally under-reported:
   - [ ] Yes
   - [ ] No
   - [ ] Neutral

If so, to what extent do you agree with the following statements:

[PLEASE RESPOND WITH ‘STRONGLY AGREE, AGREE, NEUTRAL, DISAGREE, OR STRONGLY DISAGREE] Single select

35. Hospital management and personnel are responsible for the under-reporting of dengue:
36. Clinics and other health care facilities are responsible for the under-reporting of dengue:
   [  ] Strongly Agree  [  ] Agree  [  ] Neutral  [  ] Disagree  [  ] Strongly Disagree

37. Patients who do not seeking care at hospitals or clinics are responsible for the under-reporting of dengue:
   [  ] Strongly Agree  [  ] Agree  [  ] Neutral  [  ] Disagree  [  ] Strongly Disagree

38. Government protocol and/or policy is responsible for the under-reporting of dengue:
   [  ] Strongly Agree  [  ] Agree  [  ] Neutral  [  ] Disagree  [  ] Strongly Disagree

39. The hospital should host a training session on how to report dengue fever and other reportable diseases:
   [  ] Yes  [  ] No  [  ] Not sure

40. If such a session were held, would you attend?
   [  ] Yes  [  ] No  [  ] Not sure

41. Why or why not? [CHECK ALL THAT APPLY] Multi-select
   [  ] I am not required to report diseases  [  ] I know how to report diseases
   [  ] I am too busy  [  ] I would like to learn more  [  ] I would like to refresh my memory
   [  ] I would like know if I am doing it right  [  ] Professional development
   [  ] Add to my CV/resume  [  ] I have a day off  [  ] Other

42. Would you like to add any further comment on the topics discussed?
   ________________________________
   ________________________________
   ________________________________

THANK YOU SO MUCH FOR YOUR PARTICIPATION. YOUR CONTRIBUTION IS VERY IMPORTANT FOR OUR STUDY. IF YOU HAVE ANY FURTHER QUESTIONS PLEASE DO NOT HESITATE TO CONTACT ME. (GIVE PATIENT CARD). A SU ORDEN.
Appendix F: Policy-Maker Interview Script

Policy-Maker Interview Script

Red text: What interviewer will speak

Informed Consent:
I have invited you to take part in this research study because I am trying to learn more about dengue fever surveillance, reporting and services. You will be asked to share your thoughts and opinions freely. If at any time you do not feel comfortable answering a question, you may choose not to; you may also choose to stop at your discretion. There will be no consequences for doing so.

I am also requesting your permission to audio-record the session, so that I may review the conversations and make more detailed notes for the study. Eventually, all will be deleted from the audio-recordings, with all names, places, and other personal information remaining strictly anonymous and confidential within documents. All of your answers will be anonymized by using a special identifying tag or number in place of your name. All of the documents pertaining to the study will be kept in a locked file cabinet, and all electronic data will be backed up in encrypted computer files. Only people who are directly involved with the project will have access to the original records. When the project is completed, you will not be identifiable in any way. You will have the right to review the audio recordings if desired.

There are no direct benefits for participating in this interview. The information acquired today will be used to learn more about dengue policies within the Dominican Republic. The transcripts of this interview will not be used for any other purposes. You will not receive payment or compensation for being part of this interview.

Your participation is voluntary. You can decline to participate, and you can stop your participation at any time, if you wish to do so. By participating in the interview, this means you consent to participate in this research project. Do you have any questions? [PAUSE FOR QUESTIONS] Are you still comfortable with participating in the interview as I have just described? [PAUSE FOR CONSENT; GIVE INTERVIEWEE A CHANCE TO DECLINE] Thank you.

Please remember that there are no right or wrong answers as this interview is about your experiences and opinions.

Ok. Let’s begin the interview: [Record YOUR full name, the date, time and place of the interview. State the interviewee’s gender, department and position]

Warm Up:
1. Please describe what your role is here at __________ [Name institution/department] ______.
2. How long have you been at your position?
3. What type of training is typical for someone in your position? How long does one have to train for?
   a. Could you speak about your training experience?
Grand Tour:

4. Please describe dengue surveillance in Santo Domingo.
   a. **Probe:** Can you describe the difference between reports during outbreaks and reports during non-outbreak periods?
   b. **Probe:** What are the barriers to acquiring reports that can be used for surveillance data?

5. Are surveillance data published? If so, where, by whom, and how often?
   a. **Probe:** Please describe how surveillance reports are received and used by hospitals and the public?

6. Are hospitals required to follow a dengue reporting protocol? If so, are they evaluated for how well or often they do this?
   a. **If yes:** Please describe the evaluation procedure

Dengue Control and Prevention:

7. Who is responsible for dengue control and dengue prevention programs?
   a. **Probe:** What does dengue control and prevention consist of? And how often is it performed?
   b. **Probe:** How does dengue control and prevention differ during outbreak and non-outbreak periods?

Community:

8. Have you heard of the term “mala union”? *(If not, then explain to him/her)* What do you think about how the term is used to describe the relationship between the community and the government?
   a. **Probe:** Do you think *mala union* affects dengue control and prevention within the community? If so, how?
   b. **Probe:** What do you think can be done to improve the community’s perceptions of the government?

Final Evaluation:

9. What suggestions do you have to improve upon dengue reporting and surveillance in Santo Domingo?

Conclusion:

Thank you for participating in this research. I wish to remind you that all your information will be kept confidential. Do you have any questions before we end?

*[WAIT FOR RESPONSE]* Should you have any questions or concerns about the research, please feel free to contact Aileen Chang and/or me. If you have questions regarding your rights as a research participant, you may contact the University of Miami, Human Subject Research Office at (305) 243-3195.
Possible Further Probes: (ask these depending on how conversation goes and what topics seem to weigh more)

- What media outlets are used to disseminate dengue messages?
- What are the current messages circulating about dengue?
- How are hospital evaluations processed? How do these inform reporting and surveillance protocol?
- How often are dengue control and prevention programs evaluated?
- Is there a section of government dedicated solely to dengue fever?
- What are the barriers to sustaining current services for dengue control and prevention?
- What are the barriers to keeping them current and routine?
- How do you think government turnover affects dengue surveillance and control?