

UNIVERSAL HEALTH COVERAGE AND HIV IN THE EASTERN
CARIBBEAN

UNIVERSAL HEALTH COVERAGE AND ACCESS TO HIV TREATMENT AND
CARE IN THE EASTERN CARIBBEAN

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Lay Abstract

The dissertation recognizes the challenges with defining and measuring universal health coverage and with providing access to treatment and care for human immunodeficiency virus (HIV) in the Eastern Caribbean. The first conceptual paper documents the process of selecting indicators for universal health coverage in the Sustainable Development Goals. The second conceptual paper advances recommendations for evaluating universal health coverage. The following two studies then empirically assess the challenges with access to health care for people living with HIV in the Eastern Caribbean. The third paper shows how physicians cope with the lack of appropriate resources and highlights the issue of privacy for patients. The fourth paper uses data from St. Lucia to assess the affordability of antiretrovirals and highlights the difficulties of measuring financial affordability.

Abstract

This dissertation includes four papers— two conceptual and two empirical— on universal health coverage introduced in global health as a policy concept to improve access to health care. The conceptual papers review the selection process for the Sustainable Development Goal indicator on universal health coverage and propose parameters to guide an evaluation framework for universal health coverage. The first two papers show that including participants from as many sections of the health sector and policy community is recommended in policy formulation and evaluation, and recognize that decision-making might be slower as a result. While the first two papers focus on the third Sustainable Development Goal to achieve universal health coverage, the following two empirical papers focus on the sixth Millennium Development Goal which committed to provide universal access to treatment and care for people living with HIV. The first empirical paper shows how physicians in six Eastern Caribbean countries (Antigua and Barbuda, Dominica, Grenada, St. Kitts and Nevis, St. Lucia and St. Vincent and the Grenadines) cope with the lack of resources for treatment and care. Access was implemented broadly emphasizing the availability of HIV treatment and care while ensuring that everyone who needed antiretrovirals did not incur out-of-pocket costs. In most cases, this meant receiving care in the public system which was mostly centralized and where people living with HIV had concerns about their privacy being compromised in societies where HIV stigma was prevalent. The second empirical paper shows that in St. Lucia, third-line antiretrovirals could be unaffordable to as much as 98 % of the population, depending on how affordability is measured. The papers collectively demonstrate how the Millennium Development Goals provided an opportunity for policy learning by comparing the implementation of universal access for HIV treatment and care with universal health coverage in the Sustainable Development Goals.

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There are simply no words to express my gratitude to God for going before me, levelling the mountains, breaking down the gates of bronze and cutting through the bars of iron (Isaiah 45:2). *"When the LORD restored the fortunes of Zion, we were like those who dreamed" (Psalm 126:1).*

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Acronyms and Abbreviations

AAI	Accelerating Access Initiative
AIDS	Acquired Immune Deficiency Syndrome
ACS	Association of Caribbean States
ART	Antiretroviral therapy
ARV	Antiretroviral drug
BODT	British Overseas Dependent Territories
CARICOM	Caribbean Community
CAREC	Caribbean Epidemiology Centre
CARPHA	Caribbean Public Health Agency
CCH	Caribbean Cooperation in Health
CCHD	Caribbean Commission on Health and Development
CGCED	Caribbean Group on Cooperation in Economic Development
CHRC	Caribbean Health Research Council
CPI	Consumer Price Index
CRSF	Caribbean Regional Strategic Framework
DAI	Drug Access Initiative
DaLA	Damage and Loss Assessment
DALYs	Disability-adjusted life years
ECLAC	Economic Commission for Latin America and the Caribbean
ECOSOC	Economic and Social Council
GIPA	Greater Involvement of People Living with HIV
GDP	Gross Domestic Product
HAART	Highly active antiretroviral therapy
HAI	Health Action International
HAPU	HIV/AIDS Project Unit
HDI	Human Development Index
HIA	Health impact assessment
HiREB	Hamilton Integrated Research Ethics Board
HIV	Human immunodeficiency virus
MDG	Millennium Development Goal
MTCT	Mother-to-child transmission
MPR	Median Price Ratio
NCD	Non-communicable diseases
NSP	National strategic plan
OECS	Organization of Eastern Caribbean States

OECS PPS	Organization of Eastern Caribbean States Pharmaceutical Procurement Services
PAHO	Pan American Health Organization
PANCAP	Pan Caribbean Partnership Against HIV & AIDS
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PLHA	People Living with HIV/AIDS
PMTCT	Prevention of mother-to-child transmission
SDG	Sustainable Development Goal
SIDS	Small Island Developing States
START	Strategic Timing of Antiretroviral Treatment
TB	Tuberculosis
TCPS 2	Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans
The Global Fund	The Global Fund to Fight AIDS, Tuberculosis and Malaria
TRIPS	Trade-Related Aspects of Intellectual Property Rights
UA	Universal access
UHC	Universal health coverage
UN	United Nations
UNAIDS	Joint United Nations Program on HIV/AIDS
UNDP	United Nations Development Programme
UNGASS	United Nations General Assembly Special Session
WHO	World Health Organization

A note about terminology:

In keeping with the 2015 UNAIDS terminology guidelines and in recognition of the importance language plays in perceptions, in most cases mentions of HIV/AIDS in the dissertation could be changed to HIV in previously-published works. HIV/AIDS patients would also be referred to as people living with HIV.

Declaration of Academic Achievement

This dissertation was prepared in accordance with the guidelines of the McMaster School of Graduate Studies for a sandwich thesis consisting of papers published in peer-reviewed journals.

The author of the dissertation is the sole author of all papers included in the dissertation except for Chapter 6 which was co-authored with Dr. Michel Grignon. For this co-authored paper, the first draft of the manuscript and all data analysis in SPSS was done by Jennifer Reddock. Dr. Grignon proposed using various standards of affordability in addition to the national poverty line that was proposed in the first draft. Jennifer Reddock later proposed the “Reasonable Minimum” standard, decided on the final version, and submitted the manuscript for publication.

Introduction

Goals of universal health coverage, universal access to treatment and care for people living with HIV, and how global commitments to these goals are expressed in the policy implementation phase are the main issues raised in this dissertation. The compilation of papers spans the period when the Millennium Development Goals (MDGs) were in effect and the transitional period leading up to the Sustainable Development Goals (SDGs) that were implemented in January 2016.

The dissertation considers the policy formation process (particularly considerations that influence how global goals monitoring universal health coverage are expressed), the policy implementation phase (specifically assessments of the level of access provided by physicians tasked with ensuring universal access to HIV treatment on care), and recommendations for evaluating universal health coverage in the policy evaluation phase.

Overview of the Dissertation and Problems Addressed

The papers in this dissertation examine the issue of access to health care as presented in Goal 3 of the 2016–2030 SDGs which focusses on “good health and well-being” and Goal 6 of the 2000–2015 MDGs which aimed to “combat HIV/AIDS, malaria and other diseases” (United Nations, 2015; United Nations, 2008). The papers explore the conceptual challenges of universal health coverage (and specifically the need for precise indicators and criteria to monitor and evaluate universal health coverage), and empirically investigate the reality of access to human immunodeficiency virus (HIV) treatment and care in six countries that are not widely studied when considering access in MDG 6. The dissertation is primarily concerned with how universal

health coverage is conceptualized and measured, including how it is operationalized as a framework to ensure access to health care in the context of HIV in the Eastern Caribbean.

Each of the published papers included in the dissertation takes a different approach on aspects of universal health coverage. The first published paper is a commentary and the second is a conceptual discussion. The third and fourth papers use a mixed method approach—where the third is qualitative in nature and the fourth is a quantitative analysis of the issue of the affordability of medication that was raised in the third paper. The mixed methods approach offers both qualitative and quantitative perspectives on the implementation of access to treatment and care for people living with HIV in six countries in the Eastern Caribbean. The first two published papers included in this dissertation (Chapters 2 and 3) examine the challenges associated with conceptualizing, monitoring, and evaluating universal health coverage. The latter two published papers (Chapters 5 and 6) investigate the reality of access to health care for HIV in the Eastern Caribbean. The empirical aspect provides insight into the functioning of the health systems and the wider implications for universal health coverage, thereby offering a perspective of how some of the key considerations of universal health coverage affect the end-users who provide and possibly utilize health services.

In this dissertation, access to health care is understood as a multi-dimensional concept that encompasses the fundamental principles of availability, affordability, acceptability, and quality that are embodied in universal health coverage in the SDGs (Committee on Economic, Social and Cultural Rights, 2000; Penchansky & Thomas, 1981). However, in the sixth MDG, access is more selectively operationalized as universal access with some elements of affordability and availability (United Nations Statistics Division, n.d.). Universal health coverage—which ensures that people receive good-quality health care without endangering their

non-health-related basic consumption—is at the crux of good health policy (World Health Organization [WHO], 2005; WHO, 2010), Whether responding to an infectious or non-communicable disease, or providing preventative, curative, palliative, or rehabilitative care, the issue of how to obtain necessary, affordable, good-quality care is a basic requirement of health systems everywhere. Furthermore, the accelerated pace of costly health innovations creates financial challenges for payers—be it patients and their families or third-party public or private payers (Kumar, 2011).

Leaders of United Nations Member States underscored the urgency and relevance of access to health care and universal health coverage by including these concepts in two of the most significant global development frameworks in recent years—the MDGs and SDGs. The overarching concept in the dissertation is that universal health coverage, as proposed in the SDGs, is a more comprehensive and organized understanding of access. Even if, in theory, global goals such as the MDGs and SDGs acknowledge the importance of access in discussions about health care, this recognition must also be evident in the implementation, monitoring, and evaluation of access to health care.

The MDGs and SDGs have significant global agenda-setting and prioritization roles that both positively and negatively influence priorities, research, and policy agendas (Jaffe, 2008; Vandemoortele, 2011). Although global goals like the MDGs and SDGs have the potential to direct resources to specific diseases (and away from others) and impose cumbersome reporting demands on some countries, they also have the powerful effect of focusing global attention and funding in beneficial ways (Chan et al., 2010; Lomazzi, Borisch, & Laaser, 2014).

A 2016 UNAIDS/Kaiser Family Foundation report estimated total disbursements by donor governments on HIV to low- and middle-income countries within the MDG period from 2002 to 2015 at US\$80.3 billion (Kates, Wexler, & Lief, 2016) (see Appendix C1). A 2016 study estimates that new investments to achieve SDG 3 in low- and middle-income countries could range from US\$104 billion per year in 2016 to US\$274 billion per year from 2026 to 2030 under a progressive scenario where health system constraints limit the progress of countries towards the global targets (Stenberg et al., 2017).¹ The 2016 study also offers an estimate ranging from US\$134 billion in 2016 to US\$371 billion in 2026–2030 in an aggressive scenario where most countries attain the global targets.

Beyond the rhetorical or symbolic global impact, the significance of the 2000 Millennium Declaration and the 2030 Agenda for Sustainable Development is assessed by the reality of implementation at the individual and national levels. Implementation, by its very nature, involves everyday management decisions and confrontations with constraints and ambiguity, and is far-removed from the predictable bullet points and themes that we see in policy statements (Gilson, 2016). Because of the big picture emphasis of these global goals and declarations, the everyday constraints, challenges, and successes encountered by smaller entities (such as those addressed in the latter two papers) are sometimes overlooked.

Even though universal health coverage represents a welcome improvement from the previous application of universal access in the MDGs, the weakness of universal health coverage is the lack of concrete, on-the-ground operationalization, which was advanced in the SDGs

¹ The claim that the report is global overlooks a selection bias that excluded high-income countries and some low- and middle-income countries such as those included in Papers 3 and 4 of this dissertation.

without real evaluation criteria. Health systems need to formulate an evaluation framework for universal health coverage if they are to make progress towards the SDGs. Empirical studies of how people access treatment and care provide a better understanding of universal health coverage and how to evaluate it.

Structure of the Dissertation

The Introduction provides the context and rationale for the dissertation. Chapter 1 discusses a conceptual understanding of access, universal access, coverage, and universal health coverage. Chapters 2 and 3 are conceptual papers that examine issues linked to monitoring and evaluating universal health coverage. Specifically, Chapter 2 is a commentary that acknowledges the complexity of defining, measuring, and assessing universal health coverage. Chapter 3 proposes key parameters to consider when evaluating universal health coverage and provides guidance for building an evaluation framework for universal health coverage. Chapter 3 was created in response to the MDGs being mostly monitored but not evaluated, as well as the fact that more evaluations were being encouraged under the SDGs. Given that MDG-monitoring was done by technocrats in government statistical departments, the author proposed that evaluation frameworks should deliberately seek the input of both users and providers of health care.

Chapter 2 has been published as: **Reddock, J. (2017). Seeking consensus on universal health coverage indicators in the Sustainable Development Goals. *Journal of Health Services Research & Policy*, 22(3), 178–182. <http://dx.doi.org/10.1177/1355819617704676>**

Chapter 3 has been published as: **Reddock, J. (2017). Seven parameters for evaluating universal health coverage: Incorporating supply and demand perspectives. *International***

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<http://dx.doi.org/10.1080/20479700.2017.1287981>

Chapter 4 introduces the countries of the Organization of Eastern Caribbean States (OECS) discussed in subsequent chapters.

Chapters 5 and 6 analyze particular aspects of access to health care in the specific context of HIV in OECS. Specifically, Chapter 5 considers how physicians overcome the challenges they encounter in providing care to people living with HIV. This chapter applies the descriptive case study approach described by Yin (2011) to discuss access to treatment and care for people living with HIV within the six countries in the Eastern Caribbean.

Chapter 6 investigates the affordability of antiretroviral drugs (ARVs) in St. Lucia using different conceptualizations of affordability. This chapter takes a quantitative approach to applying different ways of conceptualizing affordability. Using various definitions of affordability, the paper determines what percentage of the population in St. Lucia would be impoverished by the purchase of first-, second-, and third-line ARVs.

Chapter 5 has been published as: **Reddock, J. (2016). Eastern Caribbean physicians' response to providing HIV/AIDS care in resource-limited settings: We've come a long way, but we're not there yet. *Journal for International Providers of AIDS Care*, 15(5), 370–379.**
<http://dx.doi.org/10.1177/2325957414525755>

Chapter 6 has been published as: **Reddock, J. & Grignon M. (2013). Calculating the affordability of antiretrovirals in St. Lucia. *West Indian Medical Journal*. 62(4), 350–356.**
<http://jia.sagepub.com/content/early/2014/06/05/2325957414525755>

Chapter 6 is the only paper that has a co-author. This paper emerged after discussions between the candidate and the committee about whether individuals in high- and upper-middle-

income countries could afford ARVs. Jennifer Reddock wrote the first draft and conducted the data analysis using IBM SPSS Statistics. Jennifer Reddock proposed using the national poverty lines, while co-author and supervisor Michel Grignon suggested using various standards of poverty. Dr. Grignon reviewed the paper and offered comments on conceptual refinements. Jennifer Reddock introduced the *Reasonable Minimum* standard to be considered as a gauge for a more realistic measurement of subsistence and submitted the article for review. Chapter 7 presents the conclusion where the papers and the implications of the research are discussed as a whole.

Methodologies and formats of published sections of the dissertation

Chapter 2 is a commentary that offers the author's observations and analysis on the selection of indicators for universal health coverage. The commentary was compiled through document reviews and monitoring of the activities of the Inter-Agency Expert Group on Sustainable Development Indicators (IAEG-SDGs). Official IAEG-SDGs documents posted on the website of the United Nations Statistics Division were reviewed. Internet live streams and recordings of meeting proceedings were also monitored to obtain information about the decision-making process for the Target 3.8 of the Sustainable Development Goals. The analysis was based on reviews of the various drafts of the universal health coverage indicators, comments and submissions by United Nations Member States and agencies submitted at meetings and on-line. Chapter 3 is a conceptual discussion which proposes the supply-demand perspective as a rationale for an inclusive evaluation process. Based on the economic principle of supply and demand, it is advanced that, on seven key dimensions, individuals on both the supply- and demand-sides of health service delivery have important perspectives to offer to evaluations on

health services being provided and utilized. The author selected the seven dimensions through a heuristic process that involved identifying the elements that are pivotal to evaluations of universal health coverage. A review of literature revealed that these dimension could have different meanings to different individuals depending on whether they were on the supply-side or demand-side of health service provision.

The qualitative case study inquiry conducted through semi-structured interviews presented in Chapter 5 offers the perspective of physicians on their experiences in providing care to people living with HIV in a resource-limited setting. Physicians were identified through a snowball sampling process that started with the central office coordinating some HIV policy for the Organization of Eastern Caribbean States (OECS). Interviews were transcribed and then analyzed using NVIVO. The OECS is identified as a single setting (or case) where physicians offer a perspective of their experience of providing care to people living with HIV. The qualitative process allows for description of interactions between individuals, acknowledging context and the meanings that are acquired for the concept or issue that is being analyzed (Yin, 2010). As a case study, the chapter offers an in-depth inquiry of a specific entity in a real-world context that can credibly claim to offer more than a momentary view of a phenomenon or event (Yin, 2015). Chapter 6 addresses the question of what proportion of the population would be impoverished by prospective purchases of antiretrovirals. St. Lucia's household budgetary survey is used as the source for quantitative analysis into how much of the population could afford first-, second- and third-line antiretrovirals at current prices. Household level data was obtained from the Central Statistical Office of St. Lucia which was used in a SPSS-run simulation to see what prospective purchases of antiretrovirals would have on consumption by adults in the population. In line with the quantitative model, the analysis in this paper is

deductive (Bryman, 2012), measurable (Thomas, 2003), and by nature close-ended (Creswell & Plano Clark, 2007). This methodology is suitable to address a question such as: Based on income, how many people could possibly afford a particular medication?

Mixed methods, as a methodology used in this dissertation, combines both qualitative and quantitative approaches to answer questions related to the central issue of access to health care in the Organization of Eastern Caribbean States (OECS). Investigating a phenomenon using quantitative and qualitative data with various levels of integration of the two methods has been generally referred to as mixed methods research (Leech & Onwuegbuzie, 2009). In emergent designs (which is applied to the two empirical papers—Chapters 5 and 6), one stage of the research raises a question which is answered in subsequent phases of the research (Creswell et al., 2011). Greene et al. (1989) provide an illustration by citing Maxwell (1986) as an instance when one method was used to enhance or complement findings from the preceding method. In this dissertation, the qualitative paper addresses how physicians respond to the challenge of providing care to people living with HIV in the six OECS countries. Since the issue of unaffordable antiretrovirals was raised in Chapter 5, the following quantitative paper probes specifically what proportion of the population in St. Lucia (the only country for which data was accessible) would find various types of antiretroviral treatments to be unaffordable. The comparable sequential, exploratory, mixed methods design which is often used (when the quantitative stage is preceded by a qualitative stage) is pursued for triangulation purposes—where the two sets of results are compared (Guest and Fleming, 2014; Plano Clark & Ivankova, 2017). With the sequential exploratory design, one of the two methodologies is usually considered to be dominant. However, here triangulation is not the aim, and although the qualitative phase precedes the quantitative phase, neither methodology is treated as the dominant

one. The two papers are related in ways that are more consistent with the complementary design in mixed methods where both methodologies carry equal weight and the intent is not triangulation but to explore aspects of complementarity (Creswell & Plano Clark, 2017). According to Morgan (2019), the duplication of effort adds credibility to the qualitative results and minimizes the likelihood that the results are due to the inherent bias of either method. The quantitative phase is not employed to “prove” the qualitative results (Morgan, 2017, p. 180). Instead, the quantitative inquiry provides context for one country, and seeks results from another perspective—which are two of the possible rationales for using mixed methods (Plano Clark & Ivankova, 2017). In this case, the results of the qualitative research can stand alone. The quantitative findings do not “correct”, “compensate for”, “validate” nor “verify” the qualitative results (Morgan, 2015, p. 789). Here, the subsequent quantitative phase is proposed as a different analytical approach that can be used to answer a question relevant to the research, can be compared to the findings, and, to some extent, reinforces the credibility of the previous paper.

Ethical Considerations and Human Subjects Protection

Ethical clearance was obtained from the Hamilton Integrated Research Ethics Board (HiREB), which functions according to the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2) and conducts ethical reviews for researchers at McMaster University.² McMaster University requires researchers to comply with the terms of TCPS 2, which is the second edition of the Tri-Council Policy Statement: Ethical Conduct for Research

² More information on HiREB is available at <https://www.hireb.ca/resources/hireb-in-health-sciences-terms-of-reference>

Involving Humans. TCPS 2 is a Canadian policy created by the three Canadian federal government agencies.³

The ethics clearance ensured that there were no risks to the physicians who participated, and that research would be conducted according to ethical standards established by HiREB. In keeping with the terms of clearance obtained from HiREB, there was no review of patient records and physicians did not identify patients during the telephone interviews.

Because this research investigates the accessibility of treatment and care to a vulnerable and stigmatized population in the Eastern Caribbean, every effort was made to ensure that the privacy of people living with HIV would not be compromised. The guidelines for the ethical conduct of research are applicable whether research is conducted in Canada or another country. In addition to the ethical clearance obtained from HiREB, additional approval was required and granted by the Dominica Research Ethics Board which noted the research to be of minimal risk. Of the countries in the study, only Dominica was known to have a research ethics board. This finding was reported to HiREB and the determination was made that no further action was needed to ensure the ethical conduct of the study.

Before submitting any application to the HiREB, researchers are required to complete training provided by the Tri-Council Panel on Research Ethics for the Ethical Conduct for Research Involving Humans. After training was completed, ethical approval was obtained from

³ TCPS 2 is listed as one of the main guidelines for Canada in the International Compilation of Human Research Standards and is mentioned here <http://www.hhs.gov/ohrp/international/ethical-codes-and-research-standards/index.html>

the Research Ethics Boards before data collection began. Each participant in the qualitative study signed a consent form and was provided with information about the proposed research.

HIV as the Disease of Emphasis in Chapters 5 and 6 and Historical Significance of HIV to Global Health Policy

Increasing global mobility, along with recognition of the economic, social, political, and environmental implications of health, led to an expansion in international cooperation in health (Fidler, 2010). Since 2000, with outbreaks of new diseases, pandemics, and epidemics (both lethal and non-lethal), the HIV response is a leading example of global cooperation and efforts towards consensus in the sustained response to a disease. In 2000, when the Millennium Declaration was adopted, of the three diseases mentioned in MDG 6 (HIV, malaria, and tuberculosis), mortality and morbidity were most remarkable for HIV, prompting dire commentaries about the impact on humanity if the disease continued unabated (Black, 1986; Eberstadt, 2002; Hunter, 2003) (see Appendix D1).

Although HIV only came to the attention of epidemiologists in the two decades preceding the Declaration, the sense of urgency about HIV overshadowed the attention given to the other two MDG 6 diseases. Compared to malaria and tuberculosis, global advocacy and attention from international organizations for HIV was relatively new (see Appendix C). Even if ischemic heart disease was the leading cause of death globally in 2000 (at the start of the MDGs) and in 2015 (at the conclusion of the MDGs), HIV was a communicable disease worthy of concern, since it was the seventh leading cause of death in 2000 (WHO, 2017a) (see appendix, Table I-3). As the fourth leading cause of death globally and the third leading cause of disability-adjusted life years (DALYs), HIV was surpassed only by non-communicable diseases (NCDs) in 2000. In 2000,

HIV accounted for 6.1% of DALYs; lower respiratory infections and perinatal conditions accounted for 6.4% and 6.2% respectively of DALYs. The leading cause of death was ischemic heart disease (12.4%) (Murray et al. (2001). In 2000 and in 2015 (at the end of the MDG era), NCDs were the leading cause of death (WHO, 2016) (see appendix F1). Although NCDs carried the highest disease burden, they did not always attract the most donor funding; a disproportionate amount of developmental assistance went to HIV from 1990 to 2013 in low-income countries with a relatively high burden of disease from HIV (Dieleman et al., 2014). However, when both mortality and morbidity (more than 31 million deaths) are considered, few would deny the global impact of the disease from 2000 to 2016 (Appendix G1).

Indifference and lack of resources are arguably two factors that significantly constrain the attention a disease receives from researchers or the policy community. The exceptionalism attributed to HIV (where the case was made that because of its wide-ranging impact, it should be viewed differently and with greater urgency than other sexually transmitted diseases) made it less vulnerable to these factors (Bayer, 1991). Apart from disease burden, other factors such as government priorities, funding, and non-governmental activism influence response to diseases. Other unique characteristics supporting HIV's exceptional status were media attention and the social and economic consequences of an illness affecting people in the most productive years of life (Carmignani, Lordan, & Tang, 2012; Farmer & Kleinman, 1989; Seckinelgin, 2008; Veenstra & Whiteside, 2005).

Merson (2006) hypothesized that, around the turn of the millennium, a series of events collectively created the conditions that augmented international attention to the disease—which started with the World Bank's willingness to increase lending for HIV. Other notable factors were the 2000 International AIDS Conference in South Africa that drew attention to the need for

affordable drugs and escalating HIV-related mortality in Africa, fears that the rapid spread of the disease in countries other than Sub-Saharan Africa (particularly Russia and China) could cause economic instability in other countries, lobbying by non-governmental organizations in the United States supporting the need for global treatment, and a series of agreements from 1998 to 2000 involving pharmaceutical companies (Merson, 2006). Among those agreements of importance were the Drug Access Initiative (DAI) and the Accelerated Access Initiative (AAI) to advance access to ARVs at reduced prices in developing countries.

Because HIV is mostly sexually transmitted, discussions about prevention challenged social taboos, engaged diverse interest groups, and invited moralistic discussions about sex, drug use, and infected mothers transmitting the virus to children (Kopleman, 2002; O’Leary & Wolitski, 2009). The fear about a disease that was terminal, had different modes of transmission, and affected newborns and people in their most productive years had a uniting effect that inspired activism and eventually propelled the political leaders, and the national and global policy makers into action (Kallings, 2008).

In retrospect, the leadership of former United Nations Secretary General Kofi Annan had a galvanizing influence that focused the world’s attention on HIV. He issued a challenge for HIV to become a global health priority and for wealthy nations to become more involved in financing the global response:

In the war against HIV/AIDS, there is no us and them, no developed and developing countries, no rich and poor—only a common enemy that knows no frontiers and threatens all peoples. But we must all remember that while HIV/AIDS affects both rich and poor, the poor are much more vulnerable to infection and much less able to cope with the disease once infected (Annan, 2001, para. 6).

In 2005, HIV-related deaths peaked, and the United Nations Human Development Report stated that “the HIV/AIDS pandemic has inflicted the single greatest reversal in human development” (United Nations Development Programme, 2005, p. 3). Prior to that, in 2001, Caribbean political leaders (including representatives from the six countries featured in this dissertation) mentioned HIV as an issue “of great public interest” and recognized the prospect that HIV “would impede [economic] development through the devastation of ... human capital” (Caribbean Community, 2001a). They formed the Pan Caribbean Partnership Against HIV/AIDS to lead resource mobilization efforts and advance a united regional response to the disease (Caribbean Community, 2001b). It is the economic impact of the disease that compelled political leaders to act (UNAIDS, 2004b).

Although political leaders placed HIV on the policy agenda in the Caribbean around 2000/2001, it must be noted that the political response was lackluster nonetheless. An advocacy organization—the Caribbean Regional Network of People Living with HIV and AIDS (CRN+)—had already been in place since 1997 (Pan Caribbean Partnership Against HIV/AIDS, 2017). In a report on the 10 leading causes of death in member countries of the Caribbean Epidemiology Centre,⁴ that included the six countries examined in this dissertation, HIV was identified as the eighth leading cause of death in 1995 and as the third leading cause of death in both males and females in 2000. In 1995, HIV was the leading cause of death in the 25–44 age group (Caribbean Epidemiology Centre/CARPHA, 2005).

⁴ In 2000, the Caribbean Epidemiology Centre (CAREC) changed its name and merged with other institutional entities to become the Caribbean Public Health Agency (CARPHA). Member countries remained the same and are mentioned in Chapter 4.

According to a UNAIDS document, it was information about the economic impact of the disease that propelled governments into action (UNAIDS, 2004b). A study in 2000 by the Health Economics Department of University of the West Indies—a university in the Caribbean Community— estimated that the epidemic would cause a 6% decline in the region’s gross domestic product (GDP). A strong case for regional action on HIV was made during a meeting of the Caribbean Group on Cooperation in Economic Development (CGCED) at the World Bank headquarters in Washington, DC because the economic stakes were so high (UNAIDS, 2004b).

In 2000, the regions where HIV was most prevalent were reported to be Sub-Saharan Africa and the Caribbean (Appendix H1, Appendix I1). Updates to statistical models have resulted in a downward revision of the estimates for Sub-Saharan Africa that were applied retroactively in 2017 (UNAIDS, 2017, p. 233). It is important to see the original estimates (in real time), since these are the statistics that would have influenced policy and perceptions about HIV at that time. It must be noted that these global estimates and comparisons with the Caribbean region did not include the six countries addressed in the latter two papers in this dissertation. Because these six countries do not have populations exceeding 250,000, which is the threshold for inclusion in UNAIDS global estimates, they do not meet the criteria for inclusion in global data analysis (UNAIDS, 2014a). However, these six countries are in organizational groups (like the Pan Caribbean Partnerships against HIV/AIDS and the Pan American Health Organization) that decide on policies and allocate resources that directly affect the more populous countries, and from which they consequently also benefit.

Rationale for Selecting the Six Eastern Caribbean Countries for Chapters 5 and 6

These six OECS countries—Antigua and Barbuda, Dominica, Grenada, St. Kitts and Nevis, St. Lucia, and St. Vincent and the Grenadines—present a particular socio-demographic context that has gone unstudied so far (see Figure 1). The countries selected for this study are signatories to the MDGs and SDGs⁵ and share three characteristics that, when taken together, provide a unique context for studying access to HIV treatment and care. Firstly, these six Eastern Caribbean countries are economically vulnerable; secondly, the HIV prevalence rates are relatively low; and thirdly, their small national populations can have the effect of limiting resources for health care.

Focusing on these six countries allows an examination of the social and health-related dynamics of HIV in countries with small, closely-knit societies and relatively low HIV prevalence rates that are generally not in the purview of the tendency towards “big picture” decision-making. The small populations of these countries mean that their HIV surveillance data is not included in UNAIDS reports (UNAIDS, 2014a). Of the six countries, St. Lucia is the most populous with an estimated population in 2016 of 178,015⁶ (World Bank, 2017a). The relatively low HIV prevalence rates (usually less than one percent) result in these countries not getting the visibility that brings attention to countries with higher prevalence rates. The relatively small populations and the historical and socio-economic ties to the United Kingdom, Canada and the

⁵ There are Member States of the OECS that are British Dependent Territories and are, therefore not signatories to these global goals.

⁶ Estimated populations of the other countries are: Antigua and Barbuda: 100,963; Dominica: 73,543; Grenada: 107,317; St. Kitts and Nevis: 54,821; St. Vincent and the Grenadines: 109,643 (World Bank, 2017a).

United States suggest that emigration of qualified health professionals is a potential consideration in the countries' resource limitations.

The fact that these six countries are high-income and upper-middle-income countries (according to the World Bank income classification system) might suggest that they are economically well resourced⁷ (World Bank, 2017b). However, despite their apparent affluence, their susceptibility to natural disasters, such as hurricanes and floods, makes these economies particularly vulnerable. This vulnerability to climatic impacts is a shared characteristic of many Small-Island, Developing States (SIDS) (Turvey, 2007).

Hurricanes deliver unpredictable and largely unavoidable economic shocks that affect the health sectors of these countries. For example, the economic impact of Hurricanes Irma and Maria, which struck the Caribbean region in 2017, was estimated through post-disaster needs assessments conducted by the World Bank, the Joint United Nations Development Group, and the European Union (ACAPS, OCHA, UNDP, 2017). In Antigua and Barbuda, total damage was estimated at US\$136 million, while economic losses to property and productivity amounted to approximately US\$19 million; recovery needs were estimated at US\$222 million, of which health sector infrastructure constituted US\$7 million. In Dominica, hurricane damage was

⁷ Between 2000 and 2010, the six countries maintained their upper-middle-income status, except St. Vincent and the Grenadines, which was classified as lower-middle-income from 2000 to 2002. St. Kitts and Nevis graduated from upper-middle-income to high-income status in 2011; Antigua and Barbuda did the same in 2012. The other countries retained their upper-middle-income classification. From 2012 to 2016, the countries consistently maintained the following classifications: Antigua (high-income); Dominica (upper-middle-income); Grenada (upper-middle-income); St. Kitts and Nevis (high-income); St. Lucia (upper-middle-income); and St. Vincent and the Grenadines (upper-middle-income) (World Bank, 2017b).

estimated at US\$931 million and losses at US\$380 million, with estimated recovery needs at almost US\$1.4 billion (ACAPS, OCHA, UNDP, 2017).

The World Bank and the Government of St. Vincent and the Grenadines assessed the impact of floods that occurred in the country between November 9 and 11, 2016 and on November 28, 2016, in a rapid damage and loss assessment report (Government of St. Vincent and the Grenadines, 2016). Total damage to transportation, electricity, water and sanitation, housing, health, agriculture, industry, and commerce was estimated at US\$36.3 million (Government of St. Vincent and the Grenadines, 2016). These economic and environmental realities affect health systems and access to health care in these six countries since resources that might otherwise go towards health care might be allocated towards rebuilding and repair. Given scarce resources, governments make calculated choices and decisions about resource allocation and the social, economic and political consequences of opportunity costs.

Chapter 1: Conceptual Discussion of Access, Universal Access, Coverage and Universal Health Coverage

This section isolates the key, relevant concepts in universal health coverage and universal access. It includes a brief synopsis of the theoretical underpinnings of the two terms as they relate to their significance in the formation and implementation of the Millennium Development Goals (MDG). This chapter focuses on the literature that provides a contextual discussion of universal access and universal health coverage to highlight the similarities and differences between them as they were operationalized in the MDGs and the Sustainable Development Goals (SDGs).

The shift from universal access in the MDGs to universal health coverage in the SDGs resulted in greater responsiveness in global health policy to the broader issues of access to health care beyond just affordability. In SDG 3, universal access to treatment for the three specific diseases in the MDGs (malaria, tuberculosis, and HIV) was replaced by universal health coverage that extended beyond these diseases, with emphasis on financial health protection in SDG Target 3.8, and specifically health insurance, in Indicator 3.8.2. (United Nations Statistics Division, 2018). Universal health coverage has a deliberately dualistic focus—providing health care on the supply side and ensuring that people can pay for it on the demand-side (WHO, 2015a). The two aspects—satisfactory provision and affordability—are intended to be complementary and necessary in interpreting universal health coverage and its implementation. This is the understanding of access that is being advanced in this dissertation.

The decision was made to focus on HIV in the MDGs because of the perceived importance of the disease to global health (Kim et al, 2011). However, monitoring of MDG 6 was limited to knowledge about HIV among young people, minimizing payments at the point of

service, condom usage among high-risk groups, and increasing utilization of antiretroviral drugs (ARVs) (United Nations, 2008).⁸ Although the affordability aspect was not clearly articulated as a separate goal or target in the MDGs, there were efforts through the Accelerating Access Initiative to make ARVs more affordable in Africa and the Caribbean. By contrast, in the SDGs, all components of access—including affordability—were directly addressed in Target 3.8 of Goal 3, which expressed the intention to “achieve universal health coverage including financial risk protection and access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all” (Sustainable Development Knowledge Platform, 2017, Targets & Indicators, para. 3.8).

In 2014, the Pan American Health Organization (PAHO) proposed definitions of access, universal access, and health coverage, and outlined the conditions required for health coverage to be deemed universal. PAHO defines access as “the capacity to use comprehensive, appropriate, timely, quality health services when they are needed (Pan American Health Organization [PAHO], 2014, para. 4). Universal access is “the absence of geographical, economic, sociocultural, organizational, or gender barriers ... achieved through the progressive elimination of barriers that prevent all people from having equitable use of comprehensive health services determined at the national level” (PAHO, 2014). PAHO's (2014) definition of health coverage

⁸ MDG Indicators 6.2, 6.3, 6.5 respectively monitored condom use at last high-risk sex; the proportion of population aged 15-24 years with comprehensive correct knowledge of HIV/AIDS and the proportion of population with advanced HIV infection with access to antiretroviral drugs. Retrieved from <http://mdgs.un.org/unsd/mdg/host.aspx?Content=indicators/officialist.htm>

aligns with Penchansky and Thomas’(1981) access framework that includes the elements of 'availability, accessibility, accommodation, affordability, and acceptability.

The addition of comprehensiveness to the PAHO (2014) definition of access held health systems to the impossibly high standard of providing all health services (if this is how comprehensive as being defined). Replacing comprehensiveness with an expectation of progressive elimination of barriers would be more in line with the right to health and the idea of progressive realization of rights where States aim to provide health services that are reasonably expected to be provided under the right to health to the full extent of the available resources. (Office of the United Nations High Commissioner for Human Rights, 2008).

Even after the adoption of the SDGs and Goal 3, when it was not clear what formal definition of universal coverage would be formally advanced, there was an understanding among insiders that universal health coverage would aim to ensure that “all people and communities receive the quality health services they need, without financial hardship”⁹.

Universal Access in MDG 6 and Universal Health Coverage in SDG 3

Universal health coverage promises “financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all” (WHO, 2017b, para.3.8). Even though it is not specifically mentioned in the definition, it is expected that universal health coverage requires the right mix of health

⁹ Personal Communication, WHO Department of Health Systems and Innovation.

professionals, a supportive policy environment, and health authorities having the research, data, and information required to make health system decisions.

Universal health coverage was introduced during the MDG years when universal access was the subject of various United Nations declarations and reports (WHO, 2010). The emphasis on universal access paved the way for the prominent place that universal health coverage occupied in the “Post-2015 Agenda”—the United Nations-led strategy to advance global goals for development after the MDGs’ 2015 deadline—that was eventually formalized as the SDGs. Because the SDGs promise to build on the lessons learned from the MDGs, it is hoped that the conceptual refinements offered by universal health coverage demonstrate responsiveness to the policy levers and actions needed to ensure that all people everywhere have access to the healthcare they need. As discussed by Penchansky and Thomas, access is a multi-faceted concept (1981). Therefore, it is possible that the different components of access might not always be reflected in policy goals which are constrained and defined by institutional resources and priorities. It is hoped that the emphasis on quality, service provision, and affordability contained within the concept of universal health coverage moves closer to the goal of ensuring that people receive the health care they need without being financially overwhelmed by the cost.

Universal health coverage affirms the conditions required for delivering quality care, while ensuring that people are not subjected to financial hardship in the process (Kieny, 2017). When placed in the context of the wider 2030 Agenda for Sustainable Development, achieving universal health coverage supports efforts to advance the social determinants of health (Vega & Frenz, 2013). However, these aspirations would be inconsequential without the necessary policy advocacy, implementation, and analysis. In global health circles, universal health coverage has

become a ubiquitous, catchall term promising equitable access to health care with “the potential to transform the health and well-being of individuals and societies” (World Bank, 2018a).

Access. In spite of the seminal contribution by Penchansky & Thomas (1981) that showed that access is more than utilization, there is the tendency to assign utilization as a proxy for access (Levesque et al., 2013). This is a critique that can be specifically applied to the MDG 6. Although MDG 6 acknowledged the issue of affordability of ARVs through the Accelerating Access Initiative to reduce the cost of ARVs in some countries, only utilization was monitored in Target 6B (United Nations, 2008; Sturchio, 2004).

However, Penchansky and Thomas (1981) disaggregated access to reveal the specific components of availability, accessibility, accommodation, affordability, and acceptability. This framework was closely mirrored in the *General Comment on the Right to Health*, which itemizes the essential elements of the right to health as (a) availability; (b) accessibility with the sub-components of (i) non-discrimination, (ii) physical accessibility, (iii) economic accessibility (affordability), and (iv) information on accessibility; (c) acceptability; and (d) quality (Committee on Economic, Social and Cultural Rights, 2000).

In defining access, Norris and Aiken (2006) say that personal access to health care exists when health care is available, eligible, amenable, and compatible. Two components of this definition—availability, which is also mentioned by Penchansky and Thomas (1981), and eligibility—are aspects of access that are determined by health systems or policies, while the components of amenability and compatibility are more likely to be determined on an individual level. The amenability and compatibility components also closely mirror the concept of acceptability in the Penchansky and Thomas (1981) access framework, where amenability

reflects a person’s willingness to use the available health services, and compatibility refers to the cultural appropriateness or match between the person and the care being provided.

Universal access. Universal access refers to “the global commitment to provide HIV prevention, treatment, care and support services to all those in need, based on national targets set by countries” (UNAIDS, 2008). Target 6B of the MDGs aimed for “universal access to treatment for HIV/AIDS for all who need it” (United Nations, 2008). The 2001 *Declaration of Commitment on HIV/AIDS* highlighted the need for increased access to preventative measures, treatment, and care for people living with HIV (UNAIDS, 2001). This call for universal access to health care for people living with HIV was echoed in two other United Nations political declarations on HIV in 2006 and 2011, and was the impetus behind the 2002 Accelerating Access Initiative (United Nations, 2006a; United Nations, 2011; WHO, 2002).

Target 6B of the MDGs was introduced in 2007, seven years after the formulation of the original MDGs, when United Nations Member States reviewed progress towards the MDGS at the 2005 World Summit (United Nations, 2006b, para. 24). It was agreed that a global target was needed to advance the commitment to universal access to reproductive services and health care expressed at the 1994 International Conference on Population and Development (United Nations, 2005, paras. 57 (d), 57 (g); United Nations, 1994, para. 1.12 & Principle 8)¹⁰.

¹⁰ Target 6B was introduced after the 2005 World Summit where it was decided that new MDG targets would “[a]chieve full and productive employment and decent work for all, including women and young people” (Target 1B); “[a]chieve, by 2015, universal access to reproductive health” (Target 5B); “[a]chieve by 2010 universal access to treatment for HIV/AIDS for all those who need it” (Target 6B), and “[s]ignificantly reduce the loss of biodiversity by 2010” (Target 7B) (United Nations, 2008). The 2005 World Summit Outcome document states that HIV prevention, treatment and care has “the aim of coming as close as possible to the goal of universal access to treatment by 2010 for all those who need it ...” (United Nations, 2005, para. 57 (d)).

Assessing the precision with which universal access or universal health coverage is operationalized starts with a review of the conceptual discussions about the Goals and how the indicators were expected to measure progress towards that MDG or SDG. Technical consultations about universal access to treatment in MDG 6 concluded that individual countries could decide what portion of the population would satisfy the universal requirement (WHO, 2005). Although the MDG goal was stated as universal access, the global policy goal was actually to “come as close as possible to universal access” (United Nations, 2005, para. 57 (d)). Ultimately, the universal access target was set at 80% of those in need of treatment (United Nations Development Programme, 2013). Conversely, there was less ambiguity about how much of the population should be expected to benefit from universal health coverage. It was always clear that universal would mean *all people*—the goal was 100% coverage for service provision and financial protection (WHO, 2015b).

In 2005, although the technical consultations about universal access determined that access was to be operationalized as “a function of availability, affordability and acceptability,” this holistic application was not ultimately evident in MDG monitoring (WHO, 2005, page 11). In MDG Target 6B, access was measured and monitored as utilization, specifically the “proportion of the population with advanced HIV infection with access to antiretroviral drugs” (United Nations, 2008, Target 6.B). The indicator was simply equated or conflated with utilization, by reporting on “[t]he percentage of adults and children currently receiving antiretroviral therapy according to nationally approved treatment protocols without any accountability for the stated sub-components of availability, affordability and acceptability” (United Nations Statistics Division, n.d., para.1)

Coverage. Access and coverage are two different (but related) concepts. Most discussions about universal health coverage presuppose that there is already access to quality health care (Dmytraczenko & Almeida, 2015; PAHO, 2014). If, according to Culyer (2010), coverage refers to the health care services available to an insured person, some of what Tanahashi (1978) discusses as coverage might also be defined as access when acceptability is included. According to Tanahashi (1978), coverage comes in different forms: availability coverage (ratio of quantity of available services to the size of the population); accessibility coverage (a measurement of the capacity of services to be used based on whether it is within reasonable reach of those who should benefit from it); acceptability coverage (people's willingness to use the service based on its compatibility with personal factors, such as their religion); contact coverage (the number of people who have actually come forward for service); and effectiveness coverage (the number of people who are satisfied with the health service they received).

An important distinction between access and utilization reveals that not everyone who utilizes health care really has access in a way that satisfies all of the sub-components of access. For example, although health care is available, people might choose not to use it because the care that is offered is not acceptable to them. There also needs to be clarity on the distinction between access and coverage. The empirical chapters in this dissertation reinforce the difference between availability and utilization and amplify the importance of the disaggregated components of access. Coverage then is an important corollary to access. After the availability requirements and acceptability components have been met, coverage ensures affordability—which for many is the crucial factor in ensuring utilization of health care.

Universal health coverage. An understanding of universal health coverage is premised on the definition of coverage. According to the PAHO (2014), “[h]ealth coverage is defined as the capacity of the health system to serve the needs of the population, including the availability of infrastructure, human resources, health technologies (including medicines) and financing” (para. 5). A definition proposed for universal health coverage was initially tentative: “Universal health coverage implies that the organizational mechanisms and financing are sufficient to cover the entire population” (PAHO, 2014, para.5). Traditionally, health coverage is seen as the capacity of the health system to shield or protect individuals from the financial impact associated with health care, while universal health coverage is simultaneously the ability to provide quality health care and to utilize health services without enduring financial hardship.

Universal health coverage, as proposed by the PAHO (2014), mentions both the ability to supply health services and the ability to be able to afford to access and utilize these services,¹¹ thereby invalidating criticism that universal health coverage is overly-focused on financing¹² (WHO, 2018b). On the other hand, the repeated use of “implies” instead of “requires” in relation to universal health coverage weakens its potential impact since there is arguably an implicit rather than firm expectation that the provisions espoused by universal health coverage should be in place.¹³

¹¹ “Universal access to health and universal health coverage *imply* that all people and communities have access, without any kind of discrimination, to comprehensive, appropriate and timely, quality health services determined at the national level according to needs, as well as access to safe, effective, and affordable quality medicines, while ensuring that the use of such services does not expose users to financial difficulties, especially groups in conditions of vulnerability”. (PAHO, 2014, para. 6, emphasis added)

¹² “What UHC is not ... UHC is not just about health financing. It encompasses all components of the health system: health service delivery systems, the health workforce, health facilities and communications networks, health technologies, information systems, quality assurance mechanisms, and governance and legislation.” (WHO, 2018b, para. 2)

¹³ “Universal health coverage *implies* that the organizational mechanisms and financing are sufficient to cover the

Deciding on how to refer to universal health coverage or how to define it has historically been challenging. Early in the discourse about universal health coverage—prior to implementing the SDGs—there was some discussion about whether the term *coverage* was as easily-understood as *access*, and whether a compromise between the two nomenclatures would include the term *universal health coverage plus access* (WHO, 2013). Here, the specific critique of universal health coverage was that it was too abstract, or academic, and lacked the parsimony that would make it intellectually appealing at the grassroots level (Brolan and Hill, 2015).

In *World Health Assembly Resolution 67.14*, universal health coverage was “defined as universal access to quality prevention, promotion, treatment, rehabilitation and palliation services and financial risk protection” (World Health Assembly, 2014, para. 6). Universal health coverage is promoted as a comprehensive concept that encompasses the areas of availability, quality, affordability, and utilization (which are key components of access to health care).

Universal health coverage is defined as ensuring that all people have access to needed health services (including prevention, promotion, treatment, rehabilitation and palliation) of sufficient quality to be effective while also ensuring that the use of these services does not expose the user to financial hardship. (WHO, 2015a, para. 2).

entire population” (PAHO, 2014, para. 5, emphasis added). “Health strategies that ensure timely, quality access for all people, within the framework of ... universal health coverage, require solidarity in order to promote and provide financial protection ... toward the elimination of direct payments that constitute a barrier at the point of service” (PAHO, 2014, para. 13). “... universal access to health and universal health coverage *imply* that all people and communities have access, without any kind of discrimination, to comprehensive, appropriate and timely, quality health services determined at the national level according to needs, as well as access to safe, affordable, effective, quality medicines, while ensuring that the use of these services does not expose users to financial hardship, especially groups in conditions of vulnerability” (PAHO, 2014, Proposed Resolution, page 2, para. 2, emphasis added). Also see footnote 11.

Some have noted the changing characterizations of universal health coverage. Forman et al. (2016) catalogue the major venues where universal health coverage was introduced, such as the World Health Assembly, the World Health Report, and the UN General Assembly Resolution, to assess whether the various ways in which the concept was framed aligns with human rights standards. They document the changing characterization of universal health coverage from the initial overemphasis on financing for key health care services in the *2005 World Health Assembly Resolution (58.33)*, the political support denoted by the 2012 *United Nations General Assembly Resolution 67/81* for basic health services, and SDG Target 3.8 that commits to providing access to essential health care services (Sustainable Development Knowledge Platform, 2017; United Nations General Assembly 2012; WHA, 2005a).

As the discussion about universal health coverage shifted from key health care services to basic health services to essential health care services, there needed to be clarity about what characterized essential health care (Forman et al., 2016). Therefore, tracer interventions that advanced the minimum requirements for prevention and treatment were proposed. These tracer interventions may vary by country but all should include for prevention - FP [family planning], ANC [antenatal care] (4+ visits), immunization (full or DTP3 [three doses of the combined diphtheria, tetanus and pertussis vaccines in one year]), non-tobacco use, and adequate water source and sanitary facilities - and for treatment - skilled birth attendance, TB treatment, ARV [antiretroviral] therapy, diabetes and hypertension treatment” (WHO, 2015c).

These interventions and conditions were considered when formulating the indicator for SDG Target 3.8.2 (one of the indicators for Target 3.8), which is to “[a]chieve universal health coverage, including financial risk protection, access to quality essential health-care services and

access to safe, effective, quality and affordable essential medicines and vaccines for all” (United Nations Economic and Social Council, 2015, para. 3.8).

The metadata for the SDG universal health coverage goal pays attention to the holistic definition of health coverage and access in the health sector with a precision not seen in the MDGs for universal access. In discussions during the consultations about the universal health coverage indicator, the World Bank and WHO argued for indicators for both service coverage and financial protection that reflect both impoverishing and catastrophic expenditure (World Health Organization & World Bank Group, 2015). The divergent views on indicators for universal health coverage meant that these indicators were not finalized until well after the global indicator framework was adopted.¹⁴ Current metadata reflects indicators for coverage in the following five categories and the related areas: (a) reproductive, maternal, newborn, and child health, including family planning, antenatal care, child immunization, and pneumonia; (b) infectious disease control, including tuberculosis, HIV, insecticide treated nets for malaria, and water, sanitation and hygiene (WASH); (c) non-communicable diseases, including hypertension, diabetes, and tobacco smoking; (d) service capacity and access, including hospital bed density and access, health workforce and health worker density, health security, and the international health regulation core capacity index¹⁵ (United Nations Statistics Division, 2018a).

¹⁴ An update to the metadata for the UHC indicators was completed on May 9, 2018. See <https://unstats.un.org/sdgs/metadata/>

¹⁵ For definition and characteristics of IHR core capacity index, see <http://apps.who.int/gho/indicators/?id=4824>

Introduction to Chapter 2

The first paper titled “Seeking Consensus on Universal Health Coverage Indicators in the Sustainable Development Goals” provides a chronology of a consultative policy-making process and the efforts to achieve conceptual precision for universal health coverage indicators in the SDGs. Defining indicators for Target 3.8 of the SDGs was instrumental in the move towards conceptually clarifying universal health coverage.

This paper shows that policy-making is an incremental and deliberative process. In response to past critiques of the MDGs, the process of creating SDG indicators was deliberately inclusive. The MDG formulation process had been criticized for being a non-inclusive, top-down process that favored bureaucrats, where selected governments and international organizations were the only ones consulted for the original indicators that documented progress towards MDG goals and targets (Bond, 2006).

The SDGs, on the other hand, engaged more stakeholders (United Nations agencies, national statistical offices, civil society, and regional and international organizations) while recognizing the differences in data capacity among all countries (Adams, 2015). The emphasis was on creating universal health coverage indicators that accurately reflected the intent of the goal of good health and well-being, were easy to communicate and understand, practical in the data collection process, and could be disaggregated (Murray, 2015).

Chapter 2: Seeking consensus on universal health coverage indicators in the Sustainable Development Goals

Jennifer R. Reddock

Abstract:

There is optimism that the inclusion of universal health coverage in the Sustainable Development Goals advances its prominence in global and national health policy. However, formulating indicators for Target 3.8 through the Inter-Agency Expert Group on Sustainable Development Indicators has been challenging. Achieving consensus on the conceptual and methodological aspects of universal health coverage is likely to take some time in multi-stakeholder fora compared with national efforts to select indicators.

Introduction

The inclusion of universal health coverage targets in the Sustainable Development Goals (SDGs) ensures their place in discussions of global and national priorities for health policy. The World Health Organization highlights the importance of universal health coverage for health system strengthening, of minimizing health inequalities and of improving access to primary health care. Others argue that implementation of policies supporting universal health coverage potentially siphons attention away from the determinants of health,¹ tends to benefit more advantaged populations and promotes curative interventions rather than prevention.² However, universal health coverage extends life expectancy for all people, promotes well-being, physical and mental health,³ reinforces the right to health⁴ and advances health equity.⁵

While there has been success at giving health greater visibility in development priorities since 2015, integrating the interests of multiple stakeholders in global governance has been

challenging. Even after its initial adoption in 2016, further refinements are still possible to the SDG global indicator framework before the 2030 deadline.⁶ If global indicators for universal health coverage do not express the desired methodological and conceptual precision, it is still possible for national evaluation frameworks and indicators to reflect countries' priorities.³ SDG Target 3.8 aims to achieve universal health coverage—including financial risk protection, access to high quality essential services and access to safe, effective, high quality and affordable essential medicines and vaccines for all.³ There were delays in finalizing indicators for Target 3.8 because of the inherent difficulties in arriving at a consensus in ways that accurately conceptualize and measure universal health coverage. There has been particular dissatisfaction with the version of indicator 3.8.2 initially proposed for adoption.

Creating indicators for SDG Target 3.8

The Inter-Agency Expert Group on SDG Indicators (IAEG SDG) was established by the United Nations Statistical Commission in 2015 to create and review the global indicator framework to be adopted by the Economic and Social Council (ECOSOC) and the General Assembly.³ The IAEG SDG includes considerably more interlocutors than the previous Inter-Agency and Expert Group on the Millennium Development Goals (IAEG MDG) which had similar responsibilities for selecting the MDG indicators. The MDGs were criticized for being formulated top-down led by international agencies and a small number of influential countries.⁷

The IAEG SDG, therefore, includes not only more but also a wider cross-section of participants, thereby increasing the need for compromises to reach agreement on indicators. In 2015, an open consultation which allowed input from countries and organizations that were not members of the IAEG SDG gathered contributions from more than 600 contributors.⁸

Chronology of changes to the indicators

The indicators for universal health coverage were not easy to finalize because of conceptual and measurement-related issues. The two indicators were initially among the ‘grey’ ones which needed considerable discussion before submission for ECOSOC approval⁹, and were included in the category of indicators for which data are not easily available, even if there was an established method for obtaining the data.¹⁰

Universal health coverage is fundamentally concerned with ensuring that all ‘people should have access to the health services they need without risk of financial ruin or impoverishment’.¹¹ Universal health coverage ‘is defined as all people and all communities receiving the services they need, while ensuring that they are protected from financial hardship’.¹² Therefore, it was originally proposed to the IAEG SDG that the universal health coverage indicators should cover two main areas— access to high quality health services and financial risk protection— which would then be reflected in the two indicators initially advanced for discussion.¹³

When submitted to ECOSOC in June 2016, the first indicator (3.8.1) was proposed as ‘coverage of essential health services (defined as the average coverage of essential services based on tracer interventions that include reproductive, maternal, newborn and child health, infectious diseases, non-communicable diseases and service capacity and access, among the general and the most disadvantaged population)’. [See Table 1] This first indicator had undergone a change from the previous iteration to include a definition and list of essential health services. Tracer indicators were pre-selected based on the criteria of relevance to the epidemiological situation, the presence of cost-effective interventions, measurability, and the presence of comparable data across countries.¹⁴

SDG Target 3.8 Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.			
	January 2016	March 2016	November 2016
Indicator 3.8.1	Coverage of tracer interventions (e.g. child full immunization, ARV therapy, TB treatment, hypertension treatment, skilled attendant at birth, etc.)	Coverage of essential health services (defined as the average coverage of essential services based on tracer interventions that include reproductive, maternal, newborn and child health, infectious diseases, non-communicable diseases and service capacity and access, among the general and the most disadvantaged population)	(No further change proposed)
Indicator 3.8.2	Fraction of the population protected against catastrophic/impoverishing out-of-pocket health expenditure	Number of people covered by health insurance or a public health system per 1,000 population	Proportion of population with large household expenditures on health as a share of total household expenditure or income

Table 1: Changes to Indicators for Target 3.8 until submission to the United Nations Statistical Commission in March 2017

The second indicator (3.8.2.) generated considerably more debate. Civil society, in particular, expressed concerns that the proposed indicator did not adequately measure financial protection.^{15,16} By March 2016, the indicator had been changed from the ‘fraction of the population protected against catastrophic/impoverishing out-of-pocket health expenditure’¹⁷ to the ‘number of people covered by health insurance or a public health system per 1,000 population’.¹⁸ Predictably, this indicator was further revised as both the World Bank and World Health Organization expressed reservations.¹⁹ The subsequent proposed indicator in November 2016 for the meeting of the IAEG SDG was the “proportion of population with large household expenditures on health as a share of total household expenditure or income.”²⁰ Citing the need for robust measurement, researchers supported this change.²¹

The two universal health coverage indicators were categorized as Tier III, i.e. those for which no established method exists or for which standards and methods are being developed or tested.²² One of the factors that influenced the change from the original indicator on impoverishing and catastrophic expenditure for health care was data availability. According to the World Bank, data on who personally pays for health insurance is available for 142 countries, while only 89 countries have data on protection against catastrophic or impoverishing out-of-pocket health expenditure through household surveys.¹⁰ Limitations in data availability for global monitoring have been well-documented^{23,24} and are likely to be an issue for other indicators in the global indicator framework. There has been commitment to strengthening statistical capacity for the 2030 Agenda for Sustainable Development, particularly in low-income countries.²⁰

Conceptual challenges and changes to indicators for universal health coverage

The lead agencies for indicators for Target 3.8, the World Bank and World Health Organization, have repeatedly supported two indicators – one measuring coverage and the other measuring financial protection (with disaggregation when possible).^{13,19} The indicators combined should be able to measure the three dimensions of the so called universal coverage ‘cube’ –population coverage, service coverage for those who need it and financial protection.²⁵ Deciding on a coverage indicator (that includes tracer interventions) which is satisfactory to all countries and their people is notably difficult to produce. In order for the indicator to be meaningful, it would have to address what matters most to each country in terms of epidemiological and demographic realities, and how the need for health care is perceived by patients and providers.^{26,27}

Although the specific aspect of ‘effective coverage’ (defined as whether health services are obtained in a timely manner and at the quality necessary to obtain the desired effect and potential health gains)²⁸ is a policy ideal,²⁹ it is difficult to measure.^{14,29} The coverage indicator will not include effectiveness, and according to metadata for 3.8.1 updated in May 2016, coverage will be calculated as the number of people receiving the intervention as a percentage of people who need the intervention. This is limited to the number of people who come into contact with the health system, rather than the whole population. This shortcoming could be addressed by more descriptive country-level evaluations.

There were also some difficulties with the first iteration of 3.8.2. Health expenditure is considered to be impoverishing when it pushes households below the poverty line, or further into poverty if they are already there, and catastrophic if they spend more than a specific portion of their income on health care.³⁰ Metadata for the revised 3.8.2 indicator will not be released before

its approval by the Statistical Commission in 2017 and until the definition of large health care expenditure is resolved. Although the compromise on this indicator leans towards incorporating catastrophic expenditure, the revised indicator omits explicit mention of impoverishing or catastrophic expenditure. In the original metadata proposal¹⁷ there was some arbitrariness in measurements of catastrophic health expenditure which was proposed as 25% of total household expenditure or, using an international poverty line of \$1.25 or \$2.00 per day, that arguably had no relevance for middle and higher income countries.³¹ In the revised indicator, the figure of 25% of household expenditure was again floated but without unanimity, as some considered 10% to be an alternate benchmark of health care expenditure.³²

The previous version had seemed to raise anxieties about lop-sided monitoring of universal health coverage that emphasized reducing out-of-pocket payments for health care, and the over-simplified assumption that health financing systems guarantee access to health services.³³ In response to this critique there have been efforts at dispelling myths that suggest that universal health coverage is only about health financing.³⁴

While it might appear reasonable that insurance be used to measure the financial risk protection component of universal health coverage, the way insurance interacts with economic and policy realities makes it an unreliable metric for universal health coverage. Firstly, there is no uniformity in what is covered by health insurance across countries or even between insurance carriers within countries.^{35,36} Secondly, health insurance is also known to exacerbate inequalities since the groups that typically benefit from targeted insurance programs especially voluntary, private health insurance tend to be either employed or economically better-off.^{37,38} Social health insurance programs could similarly fail to meet population-level universal health coverage goals, particularly when mandatory enrolment places greater emphasis on the participation of

employed persons because of their ability to contribute payroll deductions.²⁹ Thirdly, health insurance itself is influenced by local market forces, is less likely to be extended to more risky clients (who most need insurance coverage), and is susceptible to differences in services covered, out-of-pocket deductibles, benefits and compensation. ³⁶Public health system coverage (which was previously proposed as a metric for 3.8.2) presents similar concerns because of unpredictable differences in the range and quality of health services offered in different countries³⁹. In some cases, administrative data showing high utilization of public health glosses over the fact that there could be a parallel requirement for out-of-pocket spending which runs contrary to the aims of universal health coverage.⁴⁰

Indicators that do not reflect the concept of access to health care will miss the mark since universal health coverage is premised on the reality of access for all.⁴¹ Health care access relies on important utilization, satisfaction and consumer awareness concepts that hinge on services being available in adequate supply, personally acceptable and affordable.⁴²

Universal coverage indicators in the future

Negotiation and consensus-building in selecting indicators are routine requirements in forming global health policy. As indicators are developed, political interests, development aspirations and scientific method have to be effectively balanced. The number of interested constituencies (such as human rights proponents, economists and patient advocacy organizations) in the discussion on indicators of universal health coverage is evidence of its importance to health and sustainable development. While the diversity of perspectives is a strength, this complexity makes consensus difficult to achieve. In contrast, national evaluation

frameworks are formulated mindful of national priorities and therefore tend to be more cohesive and quicker to establish.

There is a need for more discussion and research on international measures of poverty and their applicability to health care which would be useful not only for Target 3.8, but also the other SDG targets that measure poverty and social risk protection. Among the SDG indicators, data disaggregation⁴³ is particularly important for Goal 3, where coverage and health expenditure indicators might apply to different groups in the population who might have significantly different realities.

SDG indicators have to be chosen carefully, not only because they provide benchmarks for development and progress in achieving access to health care but also because they, like the Millennium Development Goals, have priority-setting influence.⁴⁴ Amidst the various voices and iterations of the indicators, the pre-eminent goal is to ensure that universal health coverage is attained for all people.²⁵

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Introduction to Chapter 3

The following paper, titled “Seven Parameters for Evaluating Universal Health Coverage: Including Supply and Demand Perspectives,” suggests a strategy for evaluating universal health coverage policies and efforts. Evaluation (and not just monitoring), is emphasized in the SDGs (World Health Organization & World Bank, 2015).

Evaluations allow policy-makers and other decision makers to know whether they are on-track and if recalibrations need to be made towards universal health coverage. Effective evaluation is also fundamental to ensure the effectiveness of health systems and individuals’ health and well-being.

Universal health coverage is admittedly a diffuse concept that is subject to varied interpretations. After attaining conceptual clarity, a participatory evaluation is proposed in this paper that includes the perspectives of the individuals responsible for the planning and delivery of health services (those on the supply-side), as well as those who use them (on the demand-side).

The paper does not create an evaluation framework, but it does make the case for why the evaluation process must include the perspectives of individuals on both the supply- and demand-side—mainly the differing ways to interpret necessary concepts such as sustainability, need, cost, health outcomes, a beneficial environment, quality, and human resources for health.

Chapter 3: Seven parameters for evaluating universal health coverage: Including supply and demand perspectives

JR Reddock

Abstract

Universal health coverage is included in the Sustainable Development Goals as one of the targets and is being advanced by the World Health Organization as an important concept. This paper proposes seven parameters to be considered when designing evaluations and assessments of universal health coverage. Unlike Millennium Development Goal monitoring that emphasized mostly supply-side assessments, both supply and demand-side perspectives should be included in evaluating Target 3.8 of the SDGs. The supply-and-demand sides of health services offer complementary and important perspectives that should be included in evaluations.

Introduction

The growing prominence of health in global development and as a strategic component of international cooperation is generating increasing attention to ensuring and evaluating access to healthcare (1-3). The 2030 Agenda for Development Sustainable Development which is the 15-year blueprint for global development proposes targets and goals for global monitoring of the Sustainable Development Goals (SDGs) (4). Target 3.8 of the SDGs aims to “[a]chieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all” (4).

Health services evaluations are conducted formally and informally both by those managing the supply of healthcare and those consuming healthcare. For policymakers, health

system representatives and health service users, evaluations are guided by expectations, subjective interpretations and official definitions of policy goals, frameworks and concepts (5). This paper proposes a preliminary set of key parameters to be used in assessments of universal health coverage and emphasizes that evaluations should include perspectives from both the supply side and demand sides of healthcare. These seven parameters cover most of the conceptual orbit and areas of concern when evaluating universal health coverage from both sides.

The unique features of healthcare markets must be reflected in healthcare evaluations: the combined, interacting influence of uncertainty about the effects of treatment and the occurrence of illness, the positive and negative externalities of illness and health-seeking behavior on other individuals, and information asymmetries (between individuals, healthcare providers, insurance agents and other players in the health sector) (6). These create different realities and perceptions about healthcare access, coverage and therefore the evaluation of universal health coverage. Evaluations of universal health coverage would assess the extent to which healthcare provision and utilization meet expectations.

The SDGs recommend country-led evaluations. However, these evaluations could be challenging to carry out because of the lack of conceptual clarity around universal health coverage. Theoretical discussion about evaluations of universal health coverage could provide useful input for policy makers and others involved in evaluations. Evaluations can improve health system performance through feedback processes by providing information about performance and progress towards SDG targets (7). National evaluations of the SDGs should be based on countries' unique realities and priorities (8). It is appropriate that countries have the

autonomy to decide the methodologies, format and timing of national evaluations over the SDG time span as is currently the case.

The concept of universal health coverage was originally introduced in a 2005 World Health Assembly Resolution, urging Member States to transition to ‘universal coverage’ by offering protection against financial ruin (through pre-payment, pooling of resources and risk); ensuring adequate and equitable good-quality health care infrastructures, human resources; and sustainable financing mechanisms; facilitating collaboration between public and private providers and health-financing organizations; and sharing experiences on different methods of health financing (9). Two important objectives have been proposed as the focus of universal health coverage - (i) access to the full range of health services for promotion, prevention, treatment, rehabilitation and palliative care and (ii) protection from associated impoverishment or catastrophic spending (10). However, the economic aspects of appropriate financing schemes and not jeopardizing necessary consumption in order to access health services, have overshadowed the other salient aspects of universal health coverage (11). World Health Organization (WHO) has attempted to the ‘dispel myths’ about the narrow focus of universal health coverage, countering that the focus is on all facets of the health system, not just cost (12). Further clarifications have highlighted the importance of equity in access and quality of health services (13, 14).

Universal health coverage has been criticized for lacking a clear definition of terms, and a framework that maps out how goals of equity and increased utilization would be met (15, 16). This lack of specificity undermines the effectiveness of the global commitment and evaluation of efforts towards this goal and assessments of expanded access to health services. The conceptual fuzziness relates to how universal coverage directly benefits health service users.

So far, the definition of coverage only implicitly refers to the important issue of access. If access is defined as the absence of barriers to utilization; and coverage is the capacity to serve the needs of the population, then access is a fundamental pre-requisite for coverage (17). It is expected that universal coverage would aim for ‘effective coverage’ which is coverage that health service users consider to be satisfactory; and not merely ‘contact coverage’ that measures interaction with the health system (18, 19). The various components of access (availability of health services and resources, accommodation to meet physical and time requirements of clients; affordability of services of providers and resources; acceptability as defined by clients' attitudes and preferences) (20) must be present for the policy goals of universal coverage to be achieved. To be fully operational, ‘universal access’ must also be supported by a system-wide effort to ensure coverage through financial risk protection mechanisms as is proposed under universal health coverage (21, 22).

Defining universal health coverage and access in global health

The global community’s recent attempts to prioritize and monitor healthcare delivery is expressed in the 2000-2015 Millennium Development Goals (MDGs) that highlighted ‘universal access’ (in Goal 5 for maternal health and Goal 6 for HIV/AIDS treatment), and the 2015-2030 Sustainable Development Goals’ (SDGs) where Goal 3 emphasized ‘universal health coverage’ (23). Under the MDGs, the term ‘universal’ held different meanings. For Goal 2 (access to education) and target 5B (on access to sexual and reproductive health) universal meant access for 100% of the population (11, 24) For MDG target 6B, universal access for HIV treatment initially meant ‘as close as possible to universal access’ and later referred to only 80% of those

needing treatment (25, 26). Fortunately, there is less ambiguity associated with the definition of ‘universal’ in universal health coverage, where the target is clearly stated as 100% coverage (27).

WHO has compiled a list of 100 indicators for health status that will assess risk factors, service coverage and health systems functioning (28). So far ‘candidate indicators’ have been informally proposed for reproductive and newborn health, child immunization, infectious disease and non-health sector determinants of health (and also for non-communicable diseases, infectious diseases and neglected tropical diseases) (27, 29).

The SDGs global indicator framework scheduled to be adopted in 2016 – one year after the goals – will be the precursors to official national and regional indicators (4). One shortcoming of MDG monitoring was that it was handled by national statistical offices and had limited stakeholder involvement (30). A further criticism is that the MDGs channeled attention towards monitoring the achievement of targets without substantially tackling development disparities in ways that helped those most in need (31). To their credit the SDGs, in addition to monitoring, introduce the possibility of country-led evaluations (4).

Evaluations are assessments that determine relevance, analyze why results were achieved and offer recommendations for improvement. Compared to monitoring that prioritizes the collection of data and progress reporting, evaluations are more analytical and examine the implementation process and successes at various points (32). Evaluation differs from monitoring in ways that expand accountability beyond a checklist of requirements (33).

MDG progress reports were criticized for limited civil society involvement, not adapting to local realities, and favoring input from technocrats (34). The SDGs should learn valuable planning and implementation lessons from the MDGs and also address the MDGs’ unfinished business (19, 35). When evaluating universal health coverage, input is required from both the

health system and service users' because both groups have unique perspectives on seven essential elements of health services and universal health coverage. See Table 1.

Supply and demand as an organizing concept for evaluating universal health coverage

This paper utilizes the supply-demand model of the healthcare market to emphasize the importance of evaluations by stakeholders on both the supply and demand sides in proposing key evaluation parameters for universal health coverage. Health economists have applied the law of supply and demand to healthcare, which is received at a price, and influenced by supply, demand and to some extent quality (6, 36, 37). Since the supply and demand curves have inverse gradients, and are major governing forces in healthcare, then it is reasonable to infer that the individuals on either side of supply and demand in health systems might also have different interests, that would be reflected in how they evaluate healthcare. The roles and positions of individuals in the healthcare system (both on the supply or demand-sides), influence their perspectives and ultimately their assessments of the time, effort, resources and expected results of actions associated with providing and obtaining healthcare (Figure 1).

Supply-side refers to those offering service such as health system representatives, governments and ministries of health, donors and international organizations. “Demand is defined as the quantity (or amount) of a good or service people are willing and able to buy at different prices, while supply is defined as how much of a good or service is offered at each price” (38). Individuals on the demand-side are those buying, using or consuming health services such as patients and patient organizations

On the supply-side, stakeholders who function as program implementers, donors, policymakers, politicians, and representatives of international organizations evaluate health

services on behalf of the health system (39). Health service professionals—particularly physicians who have resource allocation responsibilities sometimes have conflicting roles - acting either as advocates for consumers of healthcare or arbiters in society’s stewardship requirements (40). (See Figure 1). On one hand physicians are on the supply-side, providing services, but on the other hand are ethically obligated to make decisions in the patient’s best interest. Individual consumers also engage in evaluations of their own in choosing healthcare providers and facilities, and tracking the effectiveness of treatment (41). Although (Kutzin 2013) identifies the population and health system as the unit of analysis in the goals and objectives for universal health coverage(42), efforts should be made to ensure that the supply-side does not dominate assessments and evaluations of SDG Target 3.8 and other universal health coverage efforts.

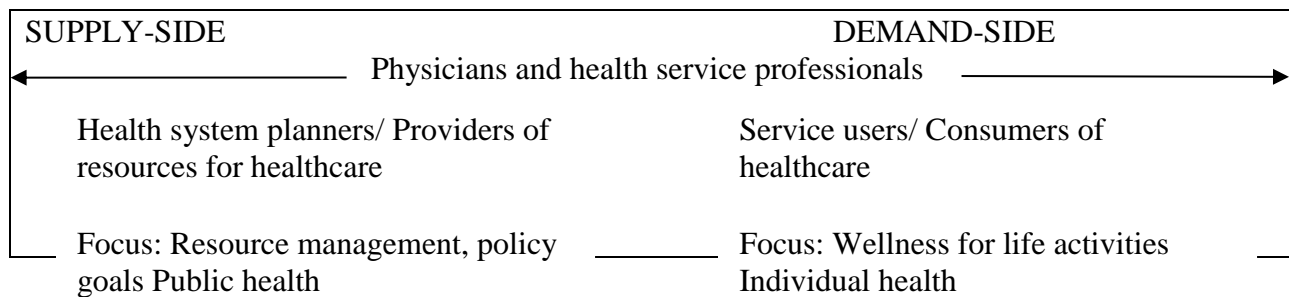


Figure 1: Differences in evaluation focus between supply-side and demand side

The value of dual perspectives in assessments of universal health coverage

Health service evaluations that include multiple perspectives and stakeholders provide a useful model for evaluations of universal health coverage. Since equity is an important concept of universal health coverage, evaluations must include the perspectives of people from different

socio-economic backgrounds (income or expenditure groups, place of residence—urban/rural, gender and ethnicities) (43).

One shortcoming of MDG monitoring was that it was handled by national statistical offices and had limited stakeholder involvement (30, 44). This “top-down” approach tends to highlight the perspectives and concerns of policymakers and technocrats on the supply-side. The dual perspective for evaluations proposed by this paper engenders more inclusivity. In the evaluation field, ‘participatory evaluation’ approaches or ‘empowerment evaluations’ in health services solicit the perspectives of end-users and under-represented populations (45).

Academic debates have validated the role of private individuals (and not just ministries of health) in health evaluations and decision-making through participatory methods known by various labels (46). ‘Public participation’, ‘citizenship engagement’, ‘public and patient involvement’, as they are characterized by various practitioners, improve accountability of health care systems, and enhance democracy (47-49). Arguments for shared decision-making cite enhanced patient autonomy (50).

There are different motivations for engaging in the evaluation of health services. Governments (and the affiliated international organizations) have a responsibility to ensure the implementation of adequate measures in health and society to support individuals’ productivity (51). Since evaluations are not entirely apolitical, a wide cross-section of participants—where all groups are given equal status reduces the possibility of particular political interest controlling evaluations (52). As seen in Figure 1, health service providers can be positioned anywhere along the continuum between supply and demand based on the functions and roles they perform in the health system.

Seven parameters as a heuristic tool for evaluating universal health coverage

Evaluations are assessments that determine relevance, analyze why results were achieved and offer recommendations for improvement. Compared to monitoring that prioritizes the collection of data and progress reporting, evaluations are more analytical and examine the implementation that expand accountability and beyond a checklist of requirements (33). MDGs (and so far even the SDGs) emphasized indicators for monitoring that did not include equal attention to evaluation (22, 54).

Table 1 provides technical guidance on evaluating universal health coverage by proposing parameters that would be useful when planning evaluations and considering the contribution of potential participants. The parameters are a non-exhaustive list and serve as a guide. Evaluation specialists would decide on the methodology, selection of participants and ensure that participatory methods are used to decide on the evaluation questions (55, 56). Evaluation exercises should be feasible, address the needs of target populations, adhere to legal and ethical concerns, and be reliable and valid (57). Evaluation of health services with feedback processes allows for implementation of lessons learned that could enhance progress towards health-related goals (58).

The seven parameters proposed in this paper serve as a heuristic tool created in response to questions of ‘What are the potential obstacles to utilizing or accessing healthcare on both sides of supply and demand?’ When thinking about health coverage, what do individuals on both sides of supply and demand value?’ The following serve as a starting point for discussions on evaluating universal health coverage, since individual countries may choose to add or select which best suit their purposes.

Table 1: Supply and demand perspectives of key parameters for evaluating universal health coverage

		Supply	Demand
Parameters/Factors of universal access to health-related goods and services	Specific area of differentiation	<u>Health system focus</u>	<u>Health service users' focus</u>
1) Sustainability of healthcare	(i) Quota	Global, national, vertical	Individual
	(ii) Duration & Continuity	Time reserved for health consultation or length of time for which funding is available	Lifetime
	(iii) Focus of health intervention	Disease-specific integrated, specialized, disease-specific	Integrated, holistic
2) Need		Capacity to benefit in a cost-effective way from intervention based on medical criteria; in terms of the expertise and resources available	Based on social, emotional constructs, perception and information
3) Cost		Cost of resources – (human and non-human) considering cost-effectiveness analysis and population equity	Direct Costs (including transportation costs) Insurance (where available) + Opportunity costs
4) Health outcomes		Mortality & Morbidity	Health-related Quality of life
5) Enabling environment for benefiting from healthcare		Social determinants of health, adequate coordination with responsible agencies	Empowered to have personal control of 'health destiny' without feeling ill-prepared because of socio-economic status and circumstances beyond one's control
6) Quality of healthcare		Adherence to clinical guidelines	Satisfaction with service, experience and usability of information
7) Human resources for health		Availability in terms of doctor to patient ratios, wait-times	Availability in terms of opening hours and wait-times

1) Sustainability of healthcare

Sustainability is defined as “the ability of the system to produce benefits valued sufficiently by users and stakeholders to ensure enough resources to continue activity with long-term benefits” (59). However, individuals utilizing healthcare on the demand side are also vested in the notion of sustainability. Although the supply and demand sides both aim for sustainable health services, tension arise because of dwindling resources on the supply side and the increasing demands confronting health systems (60). It is proposed here that sustainability, as a function of health services evaluation, has three dimensions — (i) quota (having to do with how many people are considered), (ii) duration/continuity (the period of time under evaluation) and (iii) focus (how many aspects of healthcare are considered)

(i) Coverage/Quota

Quota refers to population for which health services are being considered. On the demand side, when the international community evaluates universal access, it is usually on the basis of programs that are either global or national in scope determined by disease burden. On the supply side, the smallest and most pervasive unit of analysis is the individual. In the MDGs, the issue of scope was evident when there was parsing among global policymakers over whether it was sufficient to provide free antiretroviral treatment to ‘some’ or ‘all’ people in need (61, 62). While health systems are concerned about resources for the entire population, an individual receiving care is concerned about the provision of health services sustainability on a personal level (63). The dichotomy between individual and population health is central to the differences in perspectives between the demand and supply-sides of healthcare.

(ii) Duration and Continuity

The time dimension is also a function of sustainability evidenced by concerns about an uncertain future for health programs if donor priorities change (64). While health systems are concerned with allocating resources only for the length of an encounter with the health system, an individual's engagement with illness or health is more likely to be more proximate and continuous (65)

(iii) Focus

The history of the debate over integrated care versus vertical interventions favored by international organizations and donors further highlights the different perspectives between supply and demand. Selective interventions (or vertical care) has its origins in a global "health for all" effort which was intended to increase access to care in the 1980s (66). UNICEF rationalized the selective approach to primary health care with a narrative about the imperative to help children in poverty (67). Donors have preferred vertical, selective programs mainly because monitoring and evaluation is more easily managed and improvement in health can be directly traced to a particular intervention or program in a vertical approach (68). Supporters also say targeted, vertical programs are successful where health services are under-utilized or where there is urgent need (69).

However, there is increasing recognition by global health practitioners that the disease-specific interventions have limited impact on the individuals and ignore other diseases in the local population (70). Individuals on the demand side are more likely to prefer and derive more benefits from integrated care since it is more comprehensive and holistic in focus (71). Resource constraints on the supply side have resulted in primary care providers and health service users

limiting the length of consultations and restricting the number of health issues that can be discussed in a single visit (72, 73). Limited consultations do not always result in the perception of improved care for health service users (74).

2) Need

A perception of need for healthcare initiates procurement activity on both the demand and supply sides. The diversity in defining need reflects the variation in what stages or conditions merit a healthcare response. For some, there is a need only as long as an effective and acceptable treatment exists (75). For others, a need is present only to the extent that the individual has the capacity to benefit in terms of health functioning (76). Both of these definitions suggest that the existence of a need would not always result in restorative healthcare—whether the decision to initiate or continue with treatment is taken by the individual, the healthcare provider or the health system.

Individuals evaluate their own need for healthcare based on social constructs, emotional considerations, personal perceptions and information (77). If a person's biological and psychosocial perception of need is reinforced by beliefs and positive experiences, then that person tends to seek out and utilize health services (78). The demand for care occurs when a person who perceives a need for care actually wishes to receive care, which then leaves open the possibility that the need might remain unmet (75).

“Medically-defined need” - on which health planners are more likely to rely in resource-allocation decisions –sometimes differs from an individual's ‘self-perceived need’ (79). A self-perceived need by an individual who thinks the condition is worthy of care also faces the possibility of not finding a medical professional who agrees there is in fact a need for care (75).

In the discussion about need, the issue of supplier-induced demand is another important consideration where physicians' self-interest allows them to exploit information asymmetries and reduce their ability to act as trusted agents (6, 80). In these instances, this unreliable assessment of need by a health professional creates distortions in cases when their opinions are expected to influence the supply or demand of healthcare.

In any discussion of need in the healthcare context, cost-effectiveness and available resources are unavoidable factors that influence assessments on the supply-side of healthcare (81). This realistic approach which considers the reasonableness of the cost and whether the health condition can be improved as a result of treatment is likely to prevail on the supply-side of healthcare, which contrasts with the more likely demand-side 'humanitarian' perspective which expects that all resources must be expended to alleviate human suffering (82).

3) Cost

Cost refers to the sum of all resources required for the delivery and receiving of health care, such as the costs of procedures, therapies, and medications that include financial expenditure and non-financial outlays (83, 84). Health expenditure is used to fund hospitals and other institutions (such as residential care facilities), physicians and healthcare professionals, drugs, capital (construction, machinery, technology), public health programs, administrative functions, health research and other categories of payments that aim to prevent or remedy a health problem (85).

For health systems concerned with equity, efforts are made to ensure that spending does not jeopardize the ability to meet basic survival needs (86). The cost of treatment can be a significant barrier to access to care for individuals (87-89). Out-of-pocket costs and private insurance are unique to the demand side of healthcare. Opportunity costs are common to both the

demand and supply side although these costs are viewed differently. For the consumer of health care, these are opportunities forfeited as a result of time invested in seeking healthcare; and for the health system these are seen as opportunities to allocate resources elsewhere (90, 91).

For health systems concerned with the issue of economic equity, ensuring that less wealthy households in particular can afford healthcare without encountering financial hardship is also taken into account when considering cost. This is done in one of two ways. Either by ensuring that only a reasonable percentage of household income goes towards healthcare (in the form of general health sector taxes, social security contributions, voluntary health insurance schemes, community health insurance co-payments and other out-of-pocket expenditures) (92). The percentage of total consumption for healthcare that is defined as ‘catastrophic’ is subjectively defined (93). The second method defines ‘impoverishment’ when households are pushed into poverty estimated by national or international poverty lines (94, 95). In making evaluations about equity, health systems’ estimates are based on the number of households or the percentage of the population that are impoverished or subjected to catastrophic expenditure. On the other hand, the private individual is fundamentally concerned with the answer to the following question: “Can I sleep well at night secure in the knowledge that if anything happens to me or a member of my family, good health services will be accessible and affordable, that is, obtainable without risk of a severe and long-term impact on my financial well-being?” (42)

4) Health outcomes

The measurement of health outcomes - whether it is in terms of morbidity, mortality, or health related quality of life - is different on the demand, or supply-side of healthcare. On the demand-side, outcomes are measured based on the incentive for seeking healthcare – which is the amount of utility healthcare offers in terms of improving the quality of life and providing the

opportunity to engage in profitable or pleasurable activities (96). For utilizers of health care, health outcomes are evaluated in terms of health-related quality of life and personal assessments of functionality (97, 98). On the supply-side, the results of access are evaluated in terms of changes in health status, which for clinicians, are measured in clinical terms and sometimes quality of life indicators (99, 100).

There is some concern that healthcare is assessed mostly in terms of clinical outcomes such as mortality and physiological measures and patient's preferences and assessments are used less because they are deemed "subjective and unreliable" (101). However, "well-being" and "health-related quality of life" are other outcome indicators that are valued more on the demand side of healthcare (102).

5) Enabling environment for benefitting from healthcare

This dimension evaluates the extent to which structural factors and social support enable individuals to benefit from health services based on the importance of the social determinants of health. The determinants are conditions that govern daily life and are influenced by the convergence of economic, political and social factors (103). Differentials in the ability to have adequate education, housing, food, income, power, money and resources have implications for health equity (104). There is often the temptation to view health equity solely in terms of equity of health financing arrangements, but the ability to benefit from healthcare is influenced by a confluence of factors. Although utilization has been offered as a proxy indicator for this multi-dimensional concept, there is no single way to measure health equity (105, 106).

Governments and policy planners can coordinate a range of policy interventions and through inter-agency cooperation address the needs of most vulnerable populations. For

individuals the absence of stress, the ability to cope, and an overall sense of well-being are directly related to their ability to maximize the resources for good health. Individuals have unique and valid perspectives on whether they are fully capable of living the lives to which they aspire, and the extent to which healthcare facilitates this (107).

6) Quality of healthcare

Health care quality is assessed here as a process variable, rather than as an outcome as has been discussed previously in this paper. Although process potentially influences outcome, the emphasis here is on the direct and deliberate acts involved in providing and accessing health services. The human right to health identifies ‘quality’ as an important element of healthcare and specifies culturally-acceptable health facilities, goods and services that must be ‘scientifically and medically appropriate and of good quality’ (108). This invites both service providers and service users to decide what is appropriate based on their respective cultural, medical or scientific backgrounds. The inclusion of quality as a human rights criterion not only obligates healthcare providers to ensure that services are provided at a particular standard, but also empowers recipients of care to expect that appropriate care be provided (109).

On the supply-side, quality can be evaluated on the basis of clinical guidelines, and appropriateness criteria used in clinical decision-making (110). On the demand side, quality is accessed on the basis of satisfaction with the healthcare encounter – ranging from the location of the health facility (in terms of accessibility of the office, neighborhood in which the facility is located), inter-personal interactions and communication with the health care provider and the ability to understand medical information (20, 111-113).

The usual critiques about service users' lack of medical expertise to assess need for healthcare have also been applied to the ability to evaluate the quality of medical services (114). Others suggest that information asymmetries are less profound in the internet era, and that individuals who are able to utilize the internet are able to make astute evaluations about the quality of healthcare (115). This opinion cannot go unchallenged, since access to the internet, the accuracy of information and its relevance to each individual are all mediating factors. Without an acknowledgement of service users' ability to evaluate a health service encounter based on their expectations, healthcare assumes strong, paternalistic undertones (116).

7) Human resources for health

The shortage of health professionals between and within countries has been a persistent problem. Apart from interventions to address cost (in reaching target 6B of the Millennium Development Goals), the most concerted policy action has been the focus on human resources for health (117). Prior to 2015, it was feared that MDG health targets would have been missed because of workforce shortages (118). Some have directly linked the issue of insufficient health care providers (independent of other factors) to inadequate access to health services (119).

The problem of insufficient health human resources (particularly nurses) remains a point of discussion and analysis among the policy community (120). Health systems focus on aggregate estimates measured in doctor-patient ratios and the supply of medical personnel (121). The issue of access to a primary care provider is also measured at the individual level where service users are more likely to include further insight on the regularity, convenience and continuity of access to health service professionals (122).

Conclusion

Improving healthcare requires the involvement of a wide range of stakeholders and harmonization between health and other sectors (53). In the Sustainable Development Goals, universal health coverage is being advanced as a way of enhancing utilization of health services. Evaluating the success of universal health coverage should include the key parameters discussed in this paper with input and perspectives from both the supply and demand sides of the health system.

Even if the global indicators for monitoring universal health do not reflect their methodological preferences, countries have the autonomy to design evaluation frameworks that reflect their own priorities. The seven parameters provide some guidance that would be useful for evaluating universal health coverage.

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Chapter 4: The Eastern Caribbean as the Site for a Study on HIV Treatment and Care in

Chapters 5 and 6

History of HIV in the Organization of Eastern Caribbean States

HIV was first officially noted as a disease in 1981 by the United States Centers for Disease Control and Prevention (formerly the United States Center for Disease Control) in its *Morbidity and Mortality Weekly Report* that indicated the presence of a rare lung infection in five male patients in Los Angeles, California (CDC, 1981). The disease was first reported in the Organization of Eastern Caribbean States (OECS) countries in the following order: Grenada (1984); St. Kitts and Nevis (1984); St. Vincent and the Grenadines (1984); Antigua (1985); St. Lucia (1985); and Dominica (1987) (UNAIDS, 2010a).

Between the time of the first reported case in 1984 and antiretroviral drugs (ARV) becoming available free of charge in the public system in the OECS countries in 2002, there was limited access to life-sustaining HIV treatment. ARVs were first available free of charge in the public system through World Bank loans to three countries: Grenada in 2002; St. Kitts and Nevis in 2003; and St. Lucia in 2004 (World Bank, n.d.-c; World Bank, n.d.-d). The first disbursement of the OECS Global Fund grant, which made ARVs free in all of the OECS countries, was made in June 2006 (The Global Fund, 2006). HIV care is provided in the public system at no economic cost to patients in OECS countries and without means testing (no proof of income is required to be eligible for this).

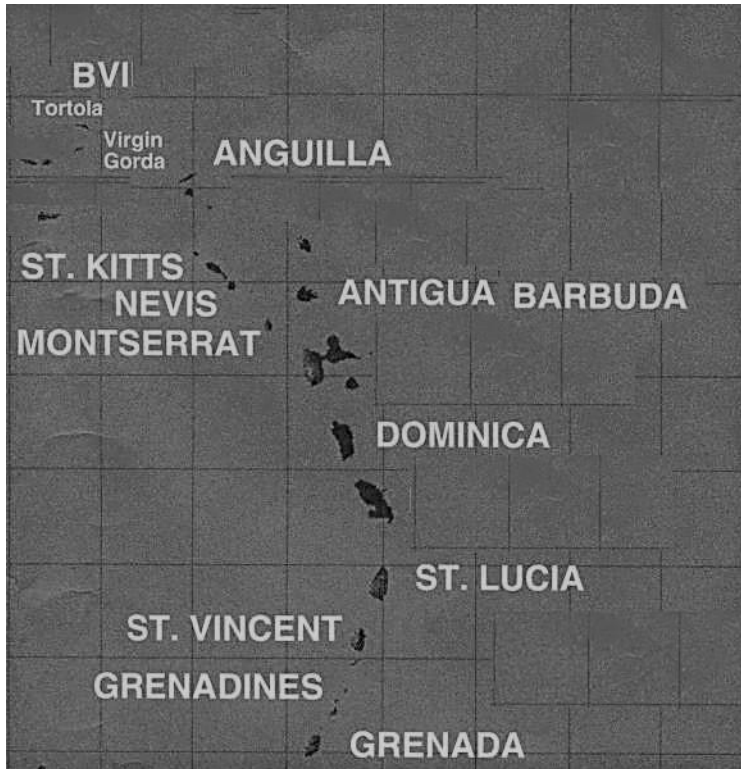


Figure 4-1. Map of the OECS

Although it is widely believed that HIV-related deaths in the OECS are underreported due to the stigma around the disease, the general trend reflected a decline in HIV-related deaths—most remarkably evident in St. Vincent and the Grenadines for the 1985–2012 period for which this data is available. (Figure 2). The under-estimating of HIV-related morbidity has been noted in various countries (Birnbaum, & Lozano, 2011; Fazito et al., 2012; Lindan et al., 1990; Roger & Wallace, 1989). Recent data comparing incidence and deaths (after 2013) are not available for the OECS and other Caribbean Public Health Agency¹⁶ (CARPHA) member countries.

¹⁶ The Caribbean Public Health Agency is the regional public health agency for the OECS and other CARPHA

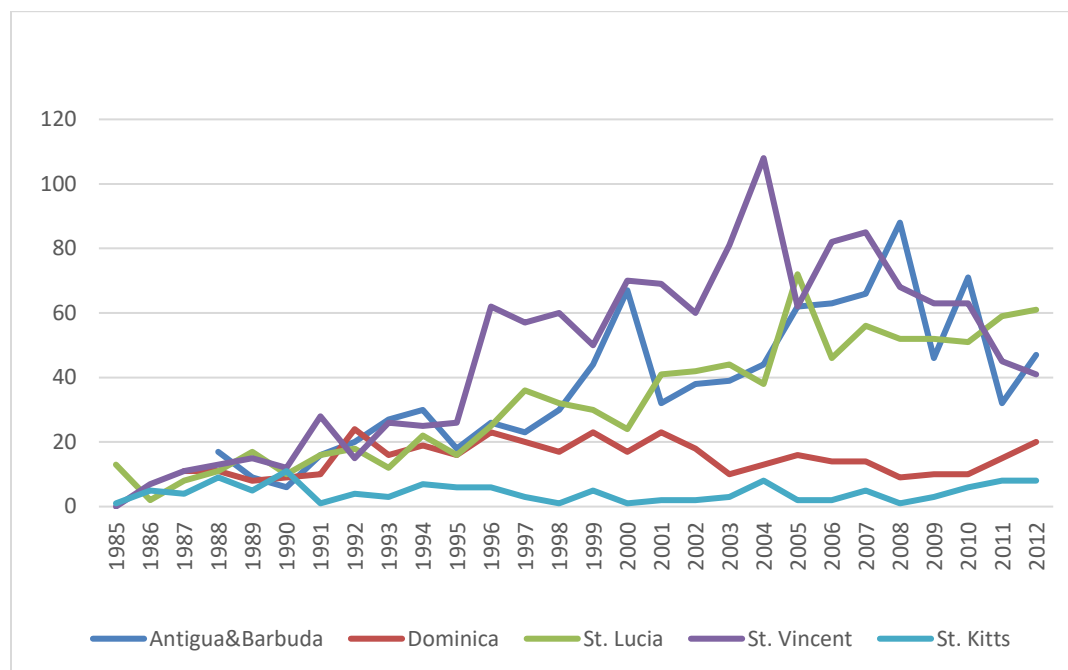


Figure 4-2. HIV cases in the six OECS countries from 1985 to 2012

The gains in longevity for people living with HIV in the OECS have been documented from as early as the 1990s (Clark, 1994; Crum et al., 2006; Deeks, Lewin, & Havlir, 2013; Fox, 1990). Over the years, with the introduction of life-sustaining ARVs, HIV has become a complex, chronic disease with people living longer with the condition and developing chronic co-morbidities, including liver and renal disease, cancers, osteoporosis, and neurocognitive and cardiovascular diseases, that are of concern for this cohort (World Health Organization ,2006a; Justice, 2010). In the OECS, chronic non-communicable diseases (NCD) (and not HIV) are the leading cause of death (Pan American Health Organization [PAHO], 2012; World Bank, 2011). Starting in 2000, CARICOM’s emphasis has been on HIV; although there has been increasing

member countries. For the institution’s mission, please see <http://carpha.org/About>. Other CARPHA members are listed in Appendix J.

recognition of the role of NCDs in contributing to premature mortality in the region.

(Abdulkadri, Cunningham-Myrie, & Forrester, 2009; Hospedales, Cummings, Gollop, & Greene, 2011).

From the early years of the HIV epidemic, the Caribbean was said to have the second highest prevalence rate after sub-Saharan Africa. While this is true, the statement omits the fact that the data estimates only report on a sub-section of the Caribbean—namely the countries with larger populations. Only countries with populations of 250,000 or more are included in UNAIDS global estimates, even if data from countries with smaller populations are submitted (UNAIDS, 2014a). The omission means that globally-reported trends might not necessarily reflect the reality in smaller countries. Furthermore, if policy solutions are designed for larger countries there may be different implementation dynamics in less populous countries. The selection preference for more populous countries is also evident in World Health Organization (WHO) research on universal health coverage. Even when the stated intent of the research was to include only the countries encountering the greatest challenges in service provision and resource mobilization for universal health coverage, the inclusion criteria of the 20 most populous lower-middle-income countries and the 20 most populous upper-middle-income countries meant the Eastern Caribbean countries were excluded¹⁷ (Stenberg et al., 2017).

Apart from the ability to attract more development assistance, population and prevalence rates also influenced research interest. There is already a significant amount of research on HIV

¹⁷ The authors justify this exclusion by saying the results aim to provide an aggregate estimate of the cost of attaining SDG3 and that the countries selected cover 95% of the total population in low-income and middle-income countries.

in sub-Saharan Africa where HIV prevalence rates are the highest (Lopez et al. 2006; WHO, UNAIDS, UNICEF, 2011). Given that prevalence rates in the six countries selected in the study are lower than those in the wider Caribbean, the countries in Chapters 5 and 6 would also not be included in research that prioritizes countries with high prevalence rates. Understandably, for HIV research and policy, the most populous countries—or those with higher prevalence rates—are more likely to guide global analytics and attract donor funding because of the anticipated return on investment of resources expended on research and programmatic interventions (Baltussen & Niessen, 2006; Lepine et al., 2015). However, given the existence of sex tourism in the Caribbean and other tourist destinations, it is ill-advised to focus on some countries and not others when assessing the response to HIV (Morse, 1995; Taylor et al., 2000).

Although selection bias in global health research excludes the countries included in this study, the human right to health and the need for information and research about health extends to all individuals, regardless of socio-economic status and the population of the country of residence or origin (Leary, 1994). Cognizant of this, two of the papers in this dissertation aim to provide some insight into the reality of the response to HIV in countries with small population sizes that might not otherwise meet the threshold for inclusion in most global calculations. The six countries in Chapter 5, which are upper-middle-income and high-income countries, provide a different context than sub-Saharan Africa. A study of the countries in Chapters 5 and 6 provides an answer to the question of whether, in the context of global commitments to universal access, the challenges are the same for physicians in low-income countries and higher-income countries in terms of HIV management and care. Issues in sub-Saharan Africa faced by physicians in the HIV sector include poverty, poor-quality health services, and recruitment of health professionals

from donor agencies offering more rewarding compensation (Hirschhorn, Oguda, Fullem, Dreesch, & Wilson, 2006; Raguin, 2016).

Case Selection

The Organization of Eastern Caribbean States.

The case selection process for this study involved identifying countries in the Caribbean that are United Nations Member States with comparable health systems that would not usually be included in global health estimates for HIV. Including the requirement for membership in the United Nations ensures a greater likelihood of a commitment to the global health declarations and of development and other data (as was used in Chapters 5 and 6) being reported to major institutions like the World Bank, UNAIDS, and WHO.¹⁸

The Caribbean is a heterogeneous region encompassing various ethnicities and language groups (Rangel, 2008) with economic diversity—ranging from a country like Haiti, which is often cited as “the poorest country in the Western Hemisphere” (one example is seen in Nováček et al., 2007, p. 1) with GDP per capita in 2017 of US\$1,814.94, to countries like the Bahamas, with GDP per capita of US\$30, 430.17¹⁹ in 2017 (World Bank, 2018c) (see Table 4-1). Amid the diversity of the Caribbean, a closer look reveals the six countries of the OECS as a subset of interest in the Caribbean region (see Figure 2). The *most-similar case selection method* (also

¹⁸ The authors justify this exclusion by saying the results aim to provide an aggregate estimate of the cost of attaining SDG3 and that the countries selected cover 95% of the total population in low-income and middle-income countries.

¹⁹ GDP per capita, PPP in (current international \$)

known as the *homogenous* or *minimum variation approach* to sampling) selects cases that are similar in the independent variables of interest, which are the delivery arrangements for physicians' services, ARVs, and laboratory and pharmacy services (Seawright & Gerring, 2008). The similarities among the OECS countries in these areas provide the homogeneity required for a case study investigation of access to treatment and care for people living with HIV (Seawright & Gerring, 2008).

The OECS countries are considered as a separate group for this study because of their interconnected economies, small population size, geographic proximity, similar health systems, small number of people living with HIV, low prevalence rates, and common management mechanisms for HIV including a drug formulary and a pooled drug procurement system. Despite their exclusion from UNAIDS prevalence estimates for the Caribbean, the migratory patterns between the OECS and high-prevalence countries in the Caribbean make the public health risk in these small populations difficult to ignore.

In applying the homogenous sampling frame to this single case study, six politically-autonomous countries of the OECS were selected for the study: Antigua and Barbuda, Dominica, Grenada, St. Kitts and Nevis, St. Lucia, and St. Vincent and the Grenadines.²⁰

²⁰ Three British Overseas Dependent Territories affiliated with the OECS were not included since two of them are only Associate Members and are not obligated to participate in all of the OECS programs. If a cross-case study approach were used, the two categories of OECS countries would have been included. Since the British Overseas Dependent Territories (BODTs) are not sovereign states, they do not have independent membership in key institutions like the United Nations and, therefore, did not directly agree to any of the commitments to universal access. Although these BODTs might be committed to ensuring access to HIV/AIDS treatment and care, unlike the independent countries they do not have the political autonomy to assent to declaration in a global forum. Moreover, the BODT do not have reporting obligations to UNAIDS, the World Bank and the Pan American Health Organization, which are key sources of information for this study. Similarities in data sources are also important for this case study selection and analysis. Unlike the other OECS countries, BODT are not eligible for HIV/AIDS funding from The Global Fund (which has been an important institution facilitating the global commitment to

Institutional arrangements and resource sharing in the OECS for HIV are a pooled drug procurement system through the Pharmaceutical Procurement Services (OECS PPS) and the HIV/AIDS Project Unit (HAPU), which was formed to administer money from the Global Fund.

They are all members of the OECS (see Figure 4.1) and coordinate the policy response to HIV through their respective ministries of health. There is central collaboration through the OECS PPS, which facilitates a pooled procurement process for ARVs, and the OECS HAPU was formed to administer financial support from the Global Fund. As OECS member states, they have common policies in political, social, and economic affairs (Organization of Eastern Caribbean States [OECS], 2010). Of the 188 countries included in the Human Development Index (HDI), the six countries have moderate levels of development and rank from 99 to 62.²¹ There is a more detailed discussion about health systems and delivery arrangements of each of the countries later in this Chapter.

In 1981, the islands in the Eastern Caribbean coalesced into a political and economic union based on their proximity, shared economic interests, and the small populations of the respective countries (OECS, 1981; World Bank, 2010). According to the Treaty of Basseterre (OECS, 1981), the OECS was formed to promote cooperation and sovereignty in foreign policy, economic integration, trade, law, and other areas of governance (See Map of the OECS, Figure 4.1). At its inception, the countries comprising the OECS were Antigua and Barbuda, Dominica,

universal access to HIV/AIDS treatment and care) and instead get funding directly from the United Kingdom.

²¹ The countries rank as follows: St. Vincent and the Grenadines (99), Dominica (96), St. Lucia (92), Grenada (79), St. Kitts and Nevis (74), and Antigua and Barbuda (62) (United Nations Development Programme, 2016).

Grenada, Montserrat, St. Kitts and Nevis, St. Lucia, and St. Vincent & the Grenadines. Since one of the original functions of the organization was "[t]o promote economic integration among the Member States" through an East Caribbean Common Market, the OECS initially included those countries in the Eastern Caribbean that shared the Eastern Caribbean dollar²² (OECS, 1981, para. (e)).

The OECS are all English-speaking countries in a wider Caribbean context where other language groups include Spanish, French, and Dutch (Rangel, 2008). The countries are also members of two of the broader political groupings of Caribbean countries, the Association of Caribbean States (ACS) and the Caribbean Community (CARICOM). Unlike CARICOM, the ACS has no programmatic involvement with HIV (ACS, n.d.) (see Figure 3).

The politically independent members of the OECS are also members of the 28-nation ACS formed to promote cooperation in matters relating to the Caribbean Sea, tourism, trade and external relations, natural disasters, and intraregional transport.

²² The two Associate Members Anguilla and the British Virgin Islands utilize the US currency and are not integrated into OECS HAPU.

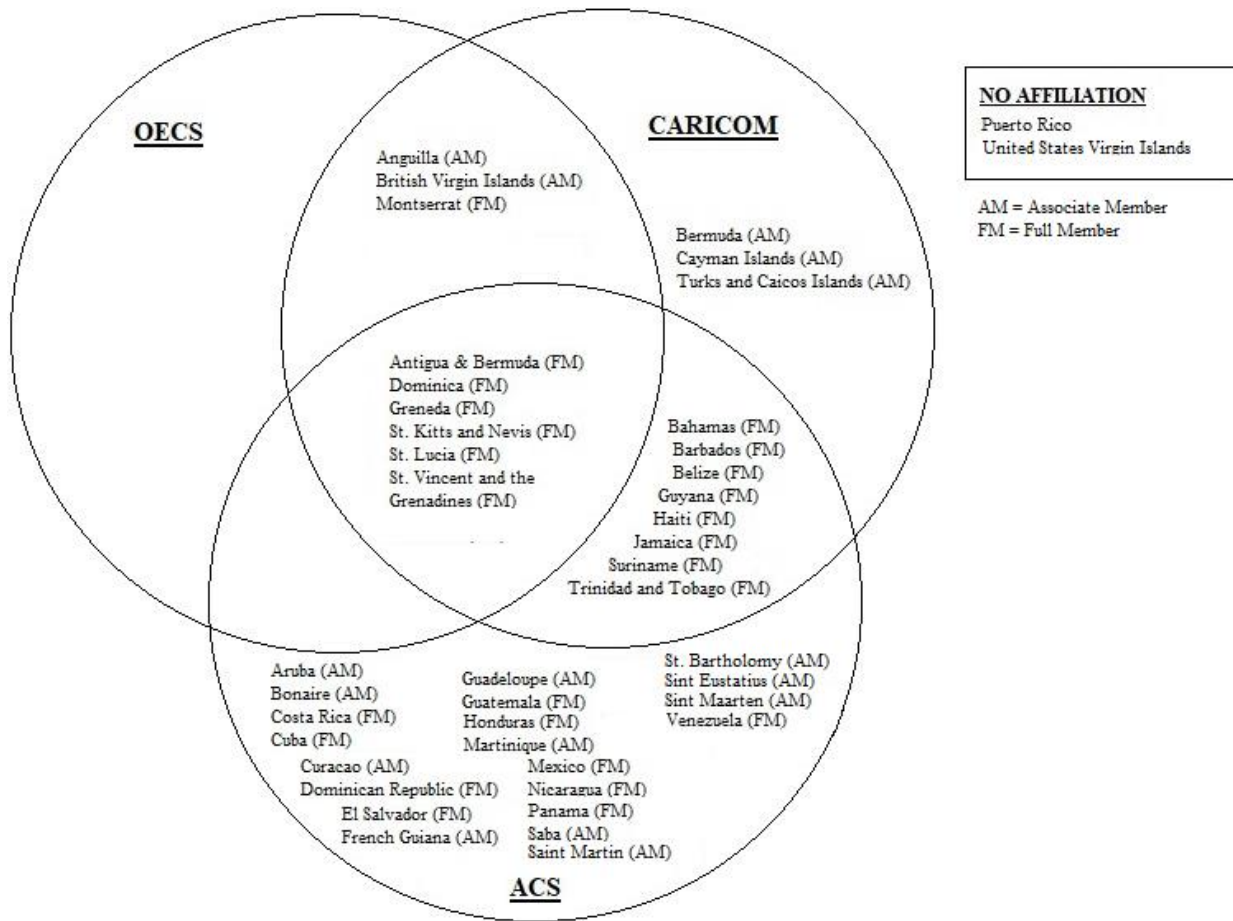


Figure 4-3. The OECS countries as a subset of the larger political groups in the Caribbean

The OECS is a subgroup of the CARICOM. The original OECS²³ treaty recognizes the previously-established Caribbean Community (OECS, 1981). CARICOM was formed in (1973) to advance economic, social, cultural, health, education, transportation, and telecommunication issues across the 13 Member States (CARICOM, 1973). With the exception of Haiti and Suriname, CARICOM countries are all members of the British Commonwealth (see Table 1 for a list of CARICOM member states).

Governmental institutions in the OECS include the Eastern Caribbean Central Bank, the Eastern Caribbean Supreme Court, and the Eastern Caribbean Civil Aviation Authority (OECS, n.d.). Since the OECS is a sub-group of CARICOM, OECS Ministers of Health are also members of the CARICOM Caucus of Health Ministers. In addition, they also hold separate meetings. Beyond a statement in the preamble of the revised treaty establishing the OECS that notes the OECS are “[m]indful of their obligations toward the wider grouping of the CARICOM Single Market and Economy,” there is no formal documentation of how the two entities collaborate (OECS, 2010, preamble, para. 5). It is understood that OECS and CARICOM do not inherently have divergent interests and do work towards common goals. Depending on the issues being discussed, the Minister for Health from OECS countries (or the minister for education or other social services) attends the meeting of the CARICOM Council for Human and Social Development, which promotes the development of health and education in CARICOM member states (CARICOM, n.d.-b).

²³ The OECS Treaty was ratified in 1981 and was revised in 2010.

CARICOM is directly involved with programmatic planning for HIV through the Pan Caribbean Partnership against HIV/AIDS (PANCAP).²⁴ PANCAP gained international recognition as the organization responding to HIV in the Caribbean (CARICOM, 2001a; United Nations, 2001). PANCAP was commissioned by CARICOM in 2001 to advocate for HIV issues with governments, to mobilize resources and to raise awareness about the disease. (PANCAP, 2017). Although the organization engages in advocacy, policy determination remains within the purview of governments in the respective member states and cannot be regulated by PANCAP.

CARICOM's Declaration of Commitment to PANCAP emphasized the importance of "[i]ncreased access to HIV prevention interventions" and "[i]ncreased access to and provision of appropriate support and care to persons infected and affected by HIV/AIDS" (CARICOM, 2001a, para. 5). PANCAP coordinates programs and is focused on building capacity to mobilize resources for HIV. However, PANCAP cannot directly determine policy on HIV in the OECS or any of the other member countries. The Caribbean Regional Strategic Framework for HIV/AIDS (CRSF) for 2002–2006 and 2008–2012 have identified areas where resources should be focused to promote an effective response to the disease. Priority areas were identified after regional consultative processes for both CRSFs. For 2002–2006, the priority areas were: advocacy, policy development and legislation; care, treatment, and support of people living with HIV; prevention of HIV transmission, with a focus on young people; prevention of HIV transmission among especially vulnerable groups—men who have sex with men, sex workers, prisoners, uniformed populations (military and police), mobile populations, and people in the workplace; prevention

²⁴ PANCAP's Coordinating Unit is located within the Directorate of Human and Social Development of the CARICOM Secretariat (PANCAP, n.d).

of mother-to-child transmission of HIV; strengthening national and regional response capability; and resource mobilization (PANCAP, 2002). For 2008–2012, the following priority areas were an expanded and coordinated multi-sectoral response to the HIV epidemic: prevention of HIV transmission; treatment, care, and support; capacity development for HIV services; and monitoring, evaluation, and research (PANCAP, 2008). In the CRSF for 2014–2018, apart from noting the commitment of PANCAP entities (that include the governments of the OECS countries mentioned in Chapter 5, civil society organizations, and development partners) to attain universal access to health services for people living with HIV, the challenge is providing lifelong care and support for increasing numbers of people in what is stated as a challenging economic and fiscal environment (CARICOM, 2014; PANCAP, n.d.-a).

Other regional health institutions, such as the Pan American Health Organization (PAHO), the Caribbean Epidemiology Centre (CAREC²⁵), and the Caribbean Health Research Council, have been involved in programs and reporting for HIV. “The Pan American Health Organization (PAHO) ... provides technical cooperation and mobilizes partnerships to improve health and quality of life in the countries of the Americas” (Pan American Health Organization, 2015, p.2). CAREC existed as a separate entity and was responsible for communicable disease surveillance for the study period in 2012 before becoming a part of the CARPHA in January 2013. “The Caribbean Epidemiology Centre (CAREC) ... was established on January 1, 1975

²⁵ As of January 2013, CAREC has become part of the Caribbean Public Health Agency (CARPHA) which also amalgamates four CARICOM-affiliated entities: the Caribbean Food and Nutrition Institute, the Caribbean Regional Drug Testing Laboratory, the Caribbean Environmental Health Institute, and the Caribbean Health Research Council (<http://www.carpha.org/carpha-docs/publications/Legal/CARPHA-IGA.pdf>).

and coordinates the regional communicable disease surveillance system for 21 English and Dutch speaking member countries” (CARPHA, n.d.-a). The Caribbean Health Research Council (CHRC) was mandated to promote and coordinate health research within CARICOM and to provide advice to their Ministries of Health and other stakeholders. CHRC is now part of the CARPHA formed in 2012 (CARPHA, n.d.-b).

Caribbean Advocacy on HIV

In CARICOM’s 2001 Nassau Declaration which affirmed that the “Health of the Region is the Wealth of the Region”, CARICOM leaders recorded their determination “to lead the charge of the Caribbean in '[f]ighting back' against HIV/AIDS and other health conditions” (CARICOM, 2001b, Article VII). In 2003, the Caribbean Community established the Caribbean Commission on Health and Development (CCHD) to review the health situation within the region following CARICOM’s 2001 Nassau Declaration. CCHD concluded in 2006 with recommendations to the CARICOM Ministers of Health. On HIV, the Commission recommended expanding treatment and confronting HIV stigma and discrimination (CARICOM, 2006; PAHO, 2006). The Commission presented its report in 2006 and did not reconvene.

The more enduring Caribbean Cooperation in Health (CCH)—a regional collaborative approach to health—was introduced at a conference of CARICOM Ministers for Health in 1984 with support from PAHO with promises to provide support for training, advice, information dissemination, policy development, research, and financing for CCH (PAHO, n.d.-a).²⁶ The

²⁶ "The CCH is a mechanism through which Member States of the Caribbean Community collectively focus action and resources over a given period towards the achievement of agreed objectives in priority areas of common concern [and] identify the approaches and activities for joint action and/or Technical Cooperation among Countries (TCC) in support of capacity building for the achievement of objectives. The goal of CCH [is] [t]o improve and sustain the

initiative was formally launched by the CARICOM Ministers of Health in 1986 when priority areas were targeted after assessing the epidemiological health profile of CARICOM countries. There have been four phases of CCH: 1986, 1999, 2010, and 2016. In CCH-[Phase]I in 1986, priority areas were environmental protection including vector control; human resource development, chronic non-communicable diseases, strengthening of the health systems; food and nutrition; and maternal and child health including population (PAHO/WHO & CARICOM, 1986). In 1988, HIV was included as a seventh priority for CCH-1 (PAHO, n.d.-a).²⁷

CARICOM Ministers of Health mandated a review of the CCH initiative and launched CCH-II in 1999 under the theme “A New Vision for Caribbean Health” (CARICOM, 1999). Eight new priority areas were established: health systems development; human resource development; family health; food and nutrition; chronic NCDs; communicable diseases; mental health; and environmental health. Sexually transmitted diseases (STD)/HIV/AIDS and tuberculosis (TB) were included among the 44 sub-priority areas in CCH-II (CARICOM, 1999). CCH-II articulated objectives in support of the following: health information and surveillance; engagement of decision-makers regarding HIV/AIDS/TB; enforcement of policies and regulations to prevent and control HIV/AIDS/STDs and TB; diagnostic, clinical, preventive, and support services for STDs/AIDS/HIV/TB; and improved accessibility (CARICOM, 1999).

health of the people of the Caribbean. This goal will result in the following: [a]dding years to life and life to years; ... [i]ncreasing equity for health within and among countries; and [m]aintaining universal access to quality care for priority problems” (CARICOM, 1999, p. vii,).

²⁷ There are no institutional records readily available providing details of HIV programs in CCH-1.

CCH-II explicitly recognized the absence of adequate treatment and care for HIV patients by acknowledging “the high case fatality rates associated with the HIV/ AIDS epidemic and in the absence of any effective treatment or prophylaxis” and stated that “it will be necessary for countries to strengthen epidemiological surveillance; create definitive programs and policies on the care and support of persons with AIDS; and strengthen educational activities in an effort to modify behaviour in the population” (CARICOM, 1999, p. 79).

CCH-III covered the period from 2010 to 2015 under the theme “Investing in Health for Sustainable Development” (CARICOM, 2010). The priority areas identified were communicable disease, NCDs, strengthening health systems, environmental health, food and nutrition, mental health, family and child health, and human resource development (CARICOM, 2010). Although not mentioned explicitly as priority areas, CCH-III noted HIV, injuries, and violence as the leading causes of death among young people and the population of productive and reproductive age. CCHI-III supported existing regional programs including those led by the Pan Caribbean Partnership against HIV/AIDS (CARICOM, 2010). The Caribbean Cooperation in Health Phase IV (CCHI-V), which is the overarching policy document for CARICOM countries covering 2016–2025, adopts an integrated world view concerning health that incorporates the sustainable development perspective that envisions an inter-ministerial, cross-disciplinary approach to health governance and a commitment to collaborate with non-health and non-traditional health partners (Caribbean Community & Caribbean Public Health Agency, 2016). Although the document lacks the granularity required for individual countries’ policies, CCHI-V articulates a recognition of the importance of universal health coverage and the health system improvement required to achieve it (Caribbean Community & CARPHA, 2016). Although not mentioned explicitly as a priority area, HIV care could be expected to fall under “health systems for universal access to

health and universal health coverage,” which has been identified as a strategic priority area in CCH-IV (Caribbean Community & CARPHA, 2016). This strategic priority area aims for good quality health services and affordable care to a larger proportion of the population (Caribbean Community & CARPHA, 2016).

Monitoring HIV in the OECS

Although from 2001–2012, UNAIDS recorded the HIV prevalence rate in the Caribbean as second only to sub-Saharan Africa,²⁸ the OECS are not included in the official UNAIDS global reports (Morison, 2001; UNAIDS 2000, UNAIDS 2013). UNAIDS’ global estimates for the Caribbean refer only to seven countries—Bahamas, Barbados, Cuba, Dominican Republic, Haiti, Jamaica, and Trinidad and Tobago. The OECS countries with smaller populations are excluded from prevalence estimates because their numbers are too small to generate statistically significant results using the UNAIDS SPECTRUM © software, which calculates prevalence for UNAIDS publications (UNAIDS, WHO, 2003). Prevalence rates in the OECS countries are not routinely calculated in the OECS, but for those countries that have calculated prevalence the estimates are not done consistently: for example, Antigua: 0.7% in 2010, 0.7% in 2011, and 0.8% in 2012; Dominica: 0.1% in 2012; Grenada: 0.7% in 2009; St. Kitts and Nevis: 0.4% in

²⁸ Sub-Saharan Africa, as defined by UNAIDS, comprises 42 countries in Africa. The UNAIDS sub-Saharan Africa countries are: Angola, Benin, Botswana, Burkina Faso, Burundi, Cameroon, Cape Verde, Central African Republic, Chad, Comoros, Côte d'Ivoire, , Democratic Republic of Congo, Equatorial Guinea, Eritrea, Ethiopia, Gabon, Gambia The, Ghana, Guinea, Guinea-Bissau Kenya, Lesotho, Liberia, Madagascar Malawi, Mali, Mauritania, Mauritius, Mozambique, Namibia, Niger, Nigeria, Rwanda, Sao Tome and Principe, Senegal, Sierra Leone, South Africa, South Sudan, Swaziland, Tanzania, Togo, Uganda, Zambia, and Zimbabwe (From UNAIDS Report on the Global AIDS epidemic, 2012).

2010; and St. Lucia in 2014: < 1%. (National AIDS Program Coordinators in the respective countries, personal communication, August 2017).

HIV monitoring and evaluation in the OECS countries are sporadic at best and estimates are not always reliably or consistently reported. The OECS countries have been identified among the data-limited countries, which due to capacity limitations have reduced reporting, monitoring, and evaluation capacity in terms of HIV (World Bank, 2008). The OECS have admitted their shortcomings in data collection, monitoring, and evaluation (Government of Antigua and Barbuda, 2007; Commonwealth of Dominica, 2012; Grenada Ministry of Health, 2008; St. Lucia, 2012; St. Kitts and Nevis, 2012; Sulzbach et al. 2012). According to PANCAP, a major challenge in policy-making is persuading the OECS and other Caribbean countries to use surveillance information to inform decision making (PANCAP, 2010).

As of March 2017, there were a total of 1,277 people in these six countries receiving ARVs through the public system as shown in Table 4-1 (OECS Pharmaceutical Procurement Services, personal communication, August 11, 2017). The combined population of the six countries is approximately 624,000, ranging from approximately 54,000 in St. Kitts and Nevis to 178,000 in St. Lucia (World Bank, 2016).²⁹

²⁹ Population in thousands: Antigua and Barbuda (100.96), Dominica (73.54), Grenada (107.32), St. Kitts and Nevis (54.82), St. Lucia (178.01), St. Vincent and the Grenadines (109.64) (World Bank, 2016).

Table 4-1

Relative numbers of people being treated for HIV in six OECS countries relative to national population in March 2017

Country	Number of people on antiretroviral treatment in the public system (Approximate total national population, 2017)	
Antigua and Barbuda	271	(100,96,000)
Dominica	69	(73,540)
Grenada	150	(107,320)
St. Kitts and Nevis	64	(54,820)
St. Lucia	353	(178,000)
St. Vincent and the Grenadines	370	(109,640)

Note. Sources: OECS Pharmaceutical Procurement Services (number of people on ART)
World Bank (Population estimates)

Since 2008, the six countries included in this study have been submitting country reports to UNAIDS and, prior to that, participated in the United Nations General Assembly Special Session (UNGASS) reporting for HIV, where progress on HIV program implementation is tracked against key indicators that are updated every two years. Ambivalence about what constitutes “Caribbean” is not limited to UNAIDS which, in addition to excluding the OECS countries from the Caribbean group, also excludes Guyana, Suriname, and Belize in the Latin America category.³⁰

³⁰ A geographic definition of Caribbean includes countries bounded by the Caribbean Sea—those between 9 and 22 degrees North and 60 and 89 degrees West (Blake 2000). This geographic definition of Caribbean admittedly results in considerable diversity and includes countries across four language groups—English, Spanish, French, and Dutch (see Appendix, Table 6). This includes Venezuela, Columbia, Panama, Costa Rica, Nicaragua, Honduras, Guatemala, Belize, Mexico, the Greater Antilles (Cuba, Jamaica, Puerto Rico, Haiti, the Dominican Republic) and the Lesser Antilles (Dominica, Martinique, St. Lucia, St. Vincent and the Grenadines, Grenada and its islets, Montserrat, Anguilla, Antigua, St. Kitts and Nevis), the United States Virgin Islands, the British Virgin Islands, and Netherlands Antilles (Aruba, Bonaire and Curaçao). However, defining the Caribbean as only those countries that border the Caribbean Sea is a contested definition since this would exclude Guyana, Barbados and the Bahamas which are countries that are traditionally included in the Caribbean (Blake 2000).

Eastern Caribbean as the Site for a Study in HIV in Chapters 5 and 6

Prevention of Mother-to-Child Transmission in the OECS

Global efforts to reduce mother-to-child transmission have long been focused on the 22 most at risk countries³¹ in sub-Saharan Africa, which account for 89% of all HIV-positive pregnant women in all low- and middle-income countries (Muraguri, 2011). In the OECS countries, between the emergence of the disease in 1984 and 2012, 0.7% of total cases have been attributed to cases below 15 years of age.^{32,33} Mother-to-child transmission is reduced by testing, counselling, support, ARVs for mothers, and use of infant formula instead of breastfeeding (where it is affordable, feasible, acceptable, sustainable, and safe) (Mirza, 2012, UNAIDS, 2010b; WHO, 2003).

According to the OECS HIV Treatment Guidelines, pregnant women in the OECS are offered pre-natal and post-natal HIV tests. If tests are positive, post-test counselling for the mother and her sexual partner is offered and mothers are enrolled in an HIV care program. Obstetricians, pediatricians, and clinical care coordinators are included in the circle of care to minimize defaulting from follow-up programs and tests. HIV-positive women who are already on ARVs at the start of the pregnancy continue on their existing regimen. All newly-diagnosed

³¹ These countries in sub-Saharan Africa are: Angola, Botswana, Burundi, Cameroon, Chad, Cote d'Ivoire, Democratic Republic of the Congo, Ethiopia, Ghana, India, Kenya, Lesotho, Malawi, Mozambique, Namibia, Nigeria, South Africa, Swaziland, Tanzania, Uganda, Zambia, and Zimbabwe.

³² HIV surveillance data counts pediatric cases as all cases less than 15 years of age. Estimates specifically for mother-to-child transmission are not available.

³³ The 0.7 figure is a cumulative estimate dating to 1984.

women are given ARVs even if their CD4 count is below the usual threshold³⁴ for initiation of treatment and infants are given ARVs (as a preventive measure³⁵) for the first six weeks of life (OECS, 2013).

Management of health care and health policy in the OECS

As former British colonies and members of the British Commonwealth, the management of health care for the OECS countries is organized to closely mirror the British Westminster model, and is led by the Minister of Government for health who is a member of the governing cabinet. Administrative authority is delegated to the permanent secretary who works with other professional, technical and administrative officials including a Chief Medical Officer who coordinates health service delivery in hospitals and clinics and offers advice to the Ministry of Health (PAHO, 1997).

HIV care is provided free of charge in the public system which includes diagnostic and monitoring tests and physician services. As of December 2017, three of the countries in the study have received WHO certification of the elimination of mother-to-child transmission of HIV—Antigua and Barbuda, Dominica, and St. Lucia (WHO, 2018c). Voluntary and free HIV Testing and Counselling is a feature of all of the OECS health systems. Each country has a single clinical care coordinator who is a physician who provides care in the public system to all HIV-positive patients. ARVs are obtained through the OECS Pharmaceutical Procurement Services in St. Lucia which coordinates pooled procurement for ARVs and other pharmaceutical

³⁴ According to the OECS Treatment Guidelines, ARV treatment is usually initiated at CD4 350.

³⁵ Prophylaxis treatment of the liquid formulations of ARVs are discontinued after six weeks if infants are HIV-negative at birth.

drugs and products for the OECS countries. A National AIDS Program Coordinator in each country handles administrative and budgetary issues and coordinates with OECS HAPU and PANCAP.

For a description of the health system and services in the six countries in the study, see Appendix A and for an economic development profile of the countries see Appendix B.

Introduction to Chapter 5

The following paper, titled “Eastern Caribbean Physicians’ Response to Providing HIV Care in Resource-Limited Settings: We’ve Come a Long Way, but We’re Not There Yet,” investigates the perceptions of physicians who provide care to people living with HIV.

The paper provides an opportunity to analyze the dynamics of universal health coverage in a specific disease domain across a group of countries. Because physicians from six countries contribute to this article, there is the opportunity to identify trends in access to treatment and care in these countries. Chapter 3 of this dissertation discussed the importance of evaluating universal health coverage and including participants on both the supply- and demand-sides of health care. As noted in Chapter 3, physicians and other health service providers are at the interface of supply and demand; their views can be more easily aligned with either side depending on the health system or the particular circumstances.

Physicians in this paper are seen as being in a “special trust relation[ship]” with their patients (Arrow, 1963, p. 966). Here they are demonstrably *perfect agents* who know the preferences of their patients and also act in their best interests (Dranove & Satterthwaite, 2000). Although economists have suggested the dynamic of physician-induced demand (where physicians prescribe treatments and procedures that a perfectly informed patient may not want to use, and do this in a systematic way to increase their income (see McGuire, 2000 for a synthesis)), there is little evidence or motive for this occurring in this study given the health system arrangements of government-salaried physicians who provide care where there is no third-party insurance carrier. As participants in the study, they also provide an assessment of

their own experience as health service providers and how they function in a resource-limited setting.

As providers of care for people living with HIV, the physicians in the study are aware of the barriers to and facilitators of access to care. Their knowledge of treatment guidelines and the standards of care allow them some insight on the availability of drugs and tests for patients. Their experience provides information for reliable analysis on the quality and affordability of care, which are two important criteria for evaluating universal health coverage. This paper demonstrates the importance of physicians as participants in future evaluations of universal health coverage in these six countries.

**Chapter 5: Eastern Caribbean physicians’ response to providing HIV/AIDS care in
resource-limited settings: We’ve come a long way, but we’re not there yet**

Jennifer Reddock

ABSTRACT

Physicians’ ability to provide care to HIV/AIDS patients in the Eastern Caribbean is influenced by economic constraints, socio-cultural norms that govern interpersonal interactions and the pervasive stigma linked to the disease. Although the economic environment determines national capacity to acquire various treatment and monitoring technologies, Eastern Caribbean physicians respond to practicing in a resource-limited setting by making choices that are influenced by the collectivist ethos that governs interpersonal relationships in this cultural setting. Through qualitative interviews, the study finds that the social stigma associated with the disease requires physicians to “go the extra mile” to provide care in ways that allow HIV/AIDS patients to protect their privacy in small, closely-networked societies.

Keywords

Physicians, Eastern Caribbean, HIV/AIDS, culture, stigma, resource-limited

Introduction

In recent decades HIV/AIDS has emerged as a disease of global significance, where from 1981 (when the disease was first noted) to 2012, about 72 million people have become infected and 35 million have died from AIDS-related illnesses (UNAIDS 2013). The global financial investment in HIV/AIDS has been unprecedented for a single disease (Kim & Gilks, 2005). From 2002-2011 donor governments and organizations committed at least US\$58.6 billion to the

global HIV/AIDS response (Kates et al. 2012). Thirty years after its emergence the impact of the disease was still tangible in the Caribbean with AIDS being the leading cause of death among people aged 20-59 (UNAIDS, 2010b). Despite global recognition and the magnitude of resources dedicated to the disease, the effectiveness of the response varies across countries and largely relies on local capacity (Maddison & Schelch, 2010).

By issuing guidelines specifically for “resource-limited settings”, the World Health Organization recognizes the global lack of uniformity in monitoring and testing capacity among countries (Gilks, 2006). In the ‘Recommendations for Anti-retroviral Treatment for Adults and Adolescents in Countries with Limited Resources’ the World Health Organization concedes that in venues referred to as being “resource-limited”, there are fewer antiretroviral drugs, and some laboratory tests are not always accessible (WHO, 2002; WHO 2003, WHO, 2006; WHO, 2010a). Although there is guidance issued to “resource-limited” countries in treating HIV/AIDS, the term “resource-limited” is used in the health domain without a definition, except by implication or on an intuitive level. This paper suggests a definition of resource-limited as having less than is required in one or more of the areas of financial, technical or human resource capacity to provide care for HIV/AIDS patients. This study proposes that physicians treating HIV/AIDS in the Eastern Caribbean practice in a resource-limited setting and focuses on how they cope with these resource limitations.

While there have been studies focusing on physicians’ contribution to the HIV/AIDS response, and challenges faced by physicians in other under-resourced settings, none of these have highlighted the Eastern Caribbean experience (Karasz et al. 2003, Idoko, 2012; Karim, 2011, Stein, et al., 2007). Health human resources constraints imposed by HIV/AIDS in Sub-Saharan Africa have been well-documented and include mortality and morbidity among health

professionals, work-time lost as a result of the sickness and death of family members affected by the disease, and public-sector inability to match the remuneration of donor agencies in competing for skilled professionals (Hirschhorn et al. 2006, Bezuidenhout et al., 2009).

The ingenuity, skill and adaptive responses demonstrated by physicians in six Organization of Eastern Caribbean States (OECS)³⁶ countries are an important component of the HIV/AIDS response in this region. Physicians' experiences are analyzed collectively because they function in similar health systems, practice in countries of geographic proximity with political, social and cultural ties, rely on a centralized drug procurement system and have a similarly-coordinated response to the disease facilitated through various regional mechanisms³⁷ travel and migration among the countries is common.

The OECS was established in 1981 to promote economic transformation, growth, employment, reduce poverty and advance development (OECS, 2011). Commitments to health are articulated in the treaty and work program (OECS, 2011; OECS 2012a).

³⁶ The countries of the Organization of Eastern Caribbean States are the politically-independent countries: Antigua Barbuda, Dominica, Grenada, St. Kitts/Nevis, St. Lucia, St. Vincent & the Grenadines and one British Dependent territory which is Montserrat. Two other British Dependent Territories – Anguilla and the British Virgin Islands – have observer status.

³⁷ The OECS HIV/AIDS Project Unit was established in 2005 to coordinate the countries' response to HIV/AIDS including the management of the grant from the Global Fund to Fight AIDS Tuberculosis and Malaria which provides antiretroviral therapy and testing services since 2004 (CARICOM, 2009). All of OECS countries in this study are full members of the Pan Caribbean Partnership Against HIV/AIDS formed in 2001 as a coordinating and capacity-building organization for the Caribbean Community.

The OECS reported its first HIV/AIDS case in 1984 (Boisson& Trotman, 2009). The first treatment for HIV/AIDS was the drug zidovudine which was approved by the United States Food and Drug Administration in 1987 and initially offered as a monotherapy (FDA, N.D.).

Like many other resource-limited settings, OECS governments did not immediately provide antiretrovirals to their patients for free. Initially the only patients obtained antiretrovirals were those who could afford the out-of-pocket costs and obtained the drug at annual costs ranging from US\$7,000- \$10,000 (JAMA, 1987)³⁸. For about 17 years after the diagnosis of the first case, zidovudine was not widely available in all of the Eastern Caribbean countries until 2004, when funding assistance from the Global Fund to Fight AIDS Tuberculosis and Malaria made these purchases possible (Ahmad, 2003; OECS, 2003; UNAIDS, 2012).

Between 2001 and 2004 three of the six countries (St. Kitts and Nevis, Grenada and St. Lucia) obtained World Bank loans for HIV/AIDS-related programs including the purchase of antiretrovirals for amounts ranging from US\$ 4.5 million to US\$ 7.9 million (World Bank, n.d.a; World Bank, n.d.b; World Bank, n.d.c).

Methodology and data collection

Physicians in this study are either salaried professionals who provide care at government clinics to HIV/AIDS patients, or private physicians who work on a fee-for-service basis and who treat HIV/AIDS and other patients as part of their general practice. Thirteen physicians were included in the study. Seven government-employed physicians who provide care to people living

³⁸ Countries' per capita GDP in 1988: Antigua/Barbuda US\$8998; Dominica US\$4416; Grenada US\$ 3711; St. Kitts/Nevis US \$6247; St. Lucia US\$3988 (World Bank World Development Indicators Retrieved from <http://www.databank.worldbank.org>)

with HIV in each of the countries were first identified by contacting the OECS coordinating agency for HIV/AIDS (one for each of the OECS countries). An additional six private physicians were identified from five of these countries by snowball sampling. Snowball sampling was used a secondary recruitment measure since there is no registry of all private physicians who provide care to HIV/AIDS patients in the Eastern Caribbean. Physicians in this study have from three to 22 years' experience treating people with HIV. The government-employed physicians provide services in a public clinic and in some cases provide care in a team-setting supported by a nurse and private physicians provide care from private offices. Physicians in this study treated approximately 91% of patients receiving antiretrovirals in the public system which was verified when the number of patients seen by each physician was compared to the number of patients receiving free antiretrovirals in each of the Eastern Caribbean. Respondents were asked to ensure that they were in a confidential location for the duration of the interview.

Interviews of approximately 60 minutes in duration were conducted by telephone, and were audio-recorded and transcribed. To enhance the credibility of the study, participants were provided with transcripts via email and given the opportunity to provide amendments to the transcript. In instances where information in the transcript was unclear, the researcher submitted follow-up questions to participants and clarifications were obtained by telephone. Ethical approval for the study was granted by McMaster University's Faculty of Health Sciences Research Ethics Board, and ethical clearance was obtained as required from the individual countries. Physicians signed a consent form outlining the study's ethical framework and indicated that their responses would be reported anonymously.

This research explores how the social environment influences care decisions by physicians in the Eastern Caribbean, and their experience of caring for HIV/AIDS patients in

conditions where all of the resources for treatment and care are not available. The qualitative method is preferred for this research which is particular, experiential and interpretive (Stake, 2010). As is typical of the qualitative process, this study explores meanings, processes and probes the response to problems (Creswell, 2007). The “framework analysis” approach is used in applied policy research that is contextual in focus by identifying the perspectives, perceptions and needs of a population by developing explanations after identifying trends in the data (Ritchie & Spencer, 1994; Pope et al., 2006; Ahluwalia & Offredy, 2005).

Consistent with the framework analysis methodology, the initial familiarization stage where the researcher reviewed the transcripts to identify the recurrent themes and main ideas was followed by an indexing stage where sections of the transcript are associated with specific themes. Sub-themes were identified during the subsequent charting stage, which was followed by the final interpretation stage (Srivastava & Thomson, 2009). Specific challenges which physicians encounter are: stigma in the profession; practicing medicine with insufficient resources; practicing medicine in small societies. The challenges were met with a range of personal accommodations by individual physicians to assist patients in access care.

See **Figure 1**.

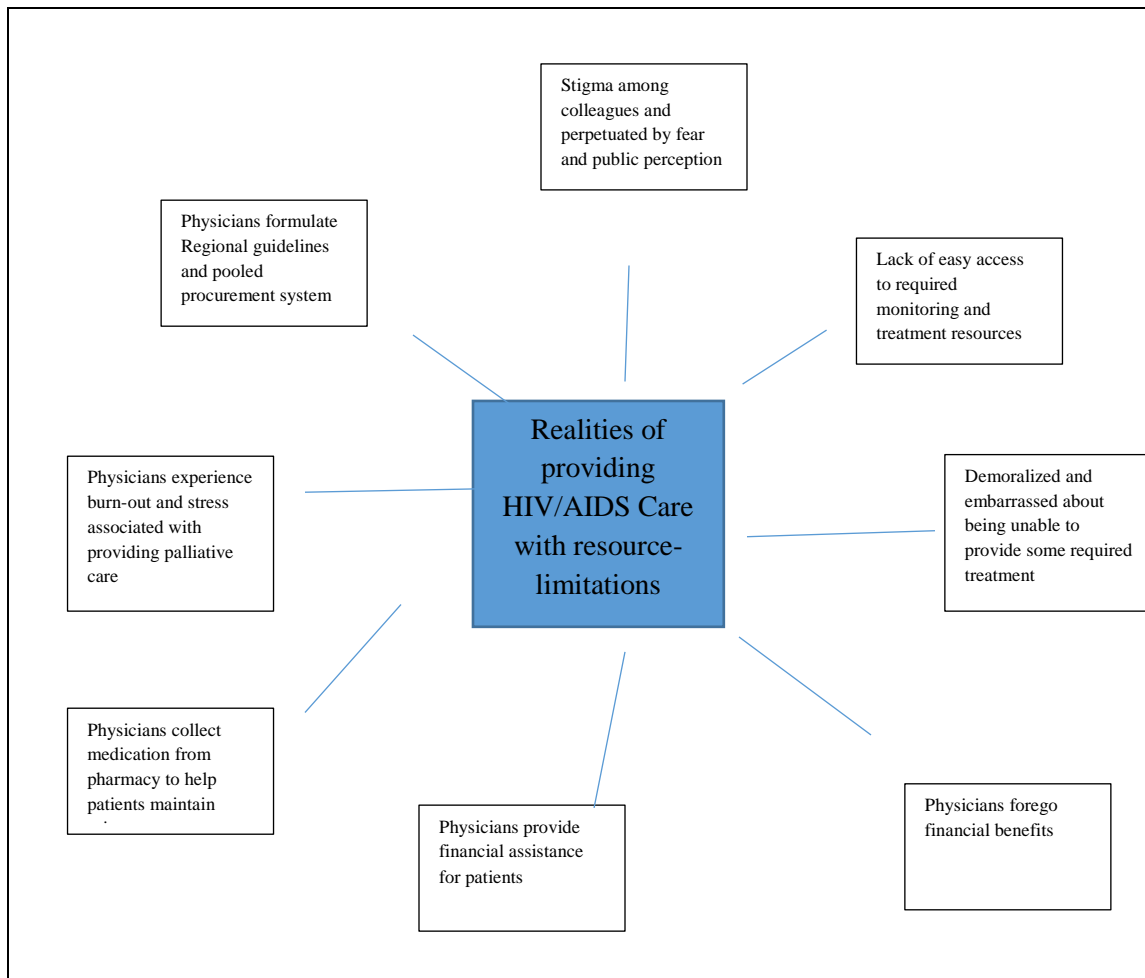


Figure 1 Physicians' responses to providing HIV Care in the Eastern Caribbean

Results

Stigma in the profession

There are mixed attitudes among the wider community of physicians about HIV/AIDS which concurrently reflects both a gradual shift towards colleagues being more accepting of patients living with HIV, and evidence of a lingering resistance about being willing to treat this group of patients. A combination of rational and irrational fears about the disease perpetuates stigma within the profession. One physician observed attitudinal biases against HIV patients during training sessions with other colleagues in the country, some of whom do not regularly treat HIV/AIDS patients. The physician hypothesized that stigmatized attitudes among

physicians persist either because physicians see themselves on some level as vulnerable to the disease, or have personal reservations about the perceived life style choices of affected patients which consequently prevent them from having an objective stance towards patients

In particular, a topic like HIV for all intents and purposes is about sex. Certainly in the Caribbean, it is about sex and not so much about intravenous drug use. Doctors are sexually active people. Because there is so much emotion, so much fear, that sometimes took over what should have been a basic clinical training. Plus, you still have physicians who associate AIDS with homosexuality, who have issues with homosexuality and who say 'I'm not treating these kind of people'. Well, it's lovely and lofty to think that all physicians are these wonderful, non-judgmental, un-biased, knowledgeable, skilled professionals. But that's just not human nature.

Physician in private practice

One physician observed less stigmatized attitudes among colleagues towards patients living with HIV over the years. This physician believes that fears about the disease have subsided over the past decade:

When we actually got into treating this disease in 1990s, some people used to be literally afraid to pass by, or touch the patients. At that point in the care and treatment for HIV, people had not yet developed a level of comfort in managing the patients and, they were happy to relinquish control and transfer their patients to someone specializing in HIV/AIDS care. And, it took a while for doctors to develop that confidence and to overcome their fear. It has become a lot easier in recent years.

Physician in private practice³⁹

³⁹ Consistent with assurances of confidentiality to participants, physicians' names and countries in which they practice

Another physician suggested that some colleagues' reluctance to treat HIV/AIDS patients reflects a general intolerance of people living with the disease that is present in the wider society. Some physicians might be concerned about their ability to retain other patients who do not want to be associated with anyone who has the disease.

For some physicians, it is not so much that they themselves mind seeing the patients, but they know that if it is known in the community that they see patients with HIV, then their other patients might stop coming to see them because these other patients don't want to share the waiting room with people who have HIV. Or maybe they'll come to suspect that the physician has HIV and conclude that's why he or she is willing to see people with HIV.

Government physician

Physicians are likely to be viewed in a one-dimensional manner – only as HIV physicians, if they treat this group of patients. In one physician's experience, this led to inaccurate assumptions that any prospective patient interacting with that physician was HIV-positive.

Even the doctor becomes stigmatized after a while. For example, as clinical care coordinator for HIV/AIDS, in addition to treating infected persons, I was involved in things like awareness among other healthcare workers and so on. Because of this public role, I was seen as the doctor who was looking out for HIV- even though, that was not the only thing I was doing. So, very soon, if a person came to the hospital asking for me,

are not included with quotations.

people might even start wondering why is this person asking for me. And a rumor could start just like that, about that person being HIV-positive.

Government physician

While there has been considerable analysis of the stigmatization of HIV patients, physicians themselves also are also targets of stigma. Another physician suggested that professionals who advocate for marginalized, high-risk groups could be similarly labeled, and sometimes encounter similar social sanctions as their patient.

I can tell you there have been times where people will call doctors certain names. It is not so much because you're treating HIV patients, but it is when you start talking about issues of sexual orientation and transactional sex, when you start advocating on behalf of these groups, that you get labeled. People then begin to say that you are immoral and refer to you in derogatory terms. That has happened to me.

Physician in private practice

Providing health care despite insufficient resources

While conditions have improved over the past decade where each country can perform CD4 tests locally; and first-and second-line antiretrovirals are currently available in each OECS country, the resource limitations were previously daunting. Between 1984 and 2001 before the country obtained a World Bank loan that allowed antiretrovirals to be provided at no cost, one physician reported doing nothing more than “tabulate the demise” of patients” because there was no access to treatment.

We have come a long way from having zero drugs. Until about 2002, we were basically just a counting system. We saw the patients; we counseled them about behavior change

and not spreading the disease. We would give them some amount of prophylaxis for opportunistic infections but, we could offer them no definitive therapy. We were just accountants – counting up the number of positive patients, counting up the number of deaths. We were totally unable to afford antiretrovirals until we could buy the much cheaper generics.

Physician in private practice

After a locally-administered HIV test proved positive, in the early years of the disease, local laboratories did not have CD4 testing equipment to accurately gauge response to treatment and the progression of the disease except through physiological and clinical symptoms. A CD4 cell count measures the concentration of the T4 cells that indicate the strength of the immune system. Although viral load tests that measure the amount of HIV [virus] were not initially available then, they are now obtained through a laboratory located in Barbados, another Caribbean country.

Back then for many years, we did not have our own CD4 counter. At that time samples were sent privately to the private lab here and cost about EC \$400.00, which therefore limited access to those who could pay or get someone to pay. We had some opportunities to send some samples to a laboratory in Barbados, but this was often a logistical nightmare with airlines. So we based our decisions on WHO clinical staging rather than based on CD4 and viral load levels.

One physician speculated that the lack of treatment fueled lingering fears among the population. The resource-limitations contributed to the disease being associated with death.

We therefore have on an academic level, knowledge that you certainly do not have to die of AIDS as soon as someone tells you that you have HIV. But, knowing that and having access to funds to offer that to our patients lagged by many, many years. And so, the fears stayed for a lot longer. Because no matter what I as a doctor said, when you got told you have HIV, you had no access to treatment.

Physician in private practice

Currently physicians in the OECS do not have access to third-line antiretrovirals for patients through the public program which provides HIV treatment and diagnostic care for patients free of cost. (Patients who require third-line ARVs have developed resistance to at least two treatment regimens and are eligible for a third-option). This option usually includes newer drugs that are still under patent and therefore more expensive.

Not having third-line drugs is the limitation – a big limitation. When the patients failed second- line, then we have struggled to figure out what to do with them because third-line is not readily available.

Physician in private practice

In the absence of a clear diagnosis for opportunistic infections, OECS HIV Guidelines advise physicians to treat empirically, listing recommended preferred and alternative therapy. Empirical treatment relies on clinical observation and involves informed hypothetical decision-

making. This form of decision-making is not unusual for resource-limited environments⁴⁰. One physician described feeling “frustrated” not being able to do enough for patients in the absence of being able to run tests to diagnose the complications

If there is a test that patients can't afford, we guess, and then treat empirically. But then you never quite know what the diagnosis is. So, I guess that's one of the things that happens in resource-limited settings, where you just cannot get the task done. It would make you feel exasperated. Because, you know you see people in front of you – it would be a minority of people who have complications – but, the few that you see, you just, feel like it's unfortunate. Because you know if they were in a more wealthy country, the diagnosis would have been made long ago and they would have been fine. But, you know. I guess that's how it is.

Government physician

On a more personal level, physicians have described being demoralized and “embarrassed” about not having resources to treat patients. One physician noted that when local resources were insufficient, patients were informed about health care options in other countries.

Sometimes it's a little embarrassing to have to tell the patients we can't afford third-line medication. We do give them options where they could get contacts overseas to get it. In some cases, they cannot afford to go overseas, so you just keep on working with what you have.

Government physician

⁴⁰ The OECS Guidelines state that, “Initiation of empiric therapy is reasonable for highly suspected conditions when the diagnosis is not immediately apparent” (OECS, 2012b, p. 51)

Because of some patients' inability to pay, some physicians in private practice treat patients at no cost after they transitioned from working in the public sector. They report giving economically-disadvantaged patients the option of not paying the consultation fee that would normally be charged to private patients.

Actually, when HIV patients come to see me they don't have to pay. But that is because I took that decision. That was my decision. I wanted patients to have the choice to go to the physician they want to see. So, I didn't them want to say, 'I'd love to come to you, but I can't afford to pay. My HIV patients, if they cannot afford to pay me, they don't have to pay.

Physician in private practice

For some physicians, treating HIV/AIDS patients has another financial dimension where physicians occasionally make small, voluntary financial contributions to patients. This response to patients' economic situation has been based on their assessment of patients' immediate need in the absence of a social safety net.

I have this one guy who sometimes, when he comes, to get his medication he might say, "Doc, I don't have bus fare home". And so, I give him bus fare home. Sometimes it's like that. There aren't very many patients in this position – those who I would say really, really have no job. There are times when he comes to my office to pick up his medication, and they are times when he would say, 'Doc, I haven't had anything to eat for the day'. And so I would give him \$10.⁴¹ to go get something to eat. When he has a job I would notice, because he looks so much better.

Physician in private practice

⁴¹ EC\$10.00 = US\$3.70

Another physician who has also provided financial assistance to patients explained that for socio-economically disadvantaged patients, the provision of free ARVs only solved one aspect of the patients' challenges. The poverty and risk factors which made them vulnerable to the disease are still a part of their lives even after entering the health system.

A lot of our patients are unemployed. Coming from an economically depressed background is a significant risk factor. Transactional sex, drug abuse and poverty are interrelated. If you do not have money, you cannot do much. People have to make choices about their money. Some mothers use their money to send their children to school instead of spending it on food for themselves. They end up not taking their medication, because taking medication on an empty stomach makes them feel un-well. It's complicated.

Government physician

Practicing medicine in small, tightly-knit societies

One physician who was a member of an advocacy group and took out a personal bank loan to provide antiretrovirals before the government program made them freely available said it was “a matter of conscience”. This physician said the imperative to act is even stronger in a small society.

Because we were with people living with HIV and AIDS – and more importantly dying from AIDS – it is very difficult to know that treatment is available and you see people that you know, and patients that you know and see them dying and know you could do something and you choose not to. That's a very uncomfortable position as a doctor to find oneself in. So that is why we responded as we did.

Physician in private practice

Another physician admitted to being “burnt out” and described being overwhelmed by the emotional demands of providing palliative care and seeing familiar patients die.

I'd say in the initial years when we had no treatment to provide, it was one of the most demoralizing periods in my life. One of the saddest periods in my life, was when a little girl who was exactly the same age as my daughter, died of AIDS. That 'knocked my socks off' for a while. Because, people don't understand the emotional toll that it takes to deal on a daily basis with patients, when at that time we had no medication. Even now, we don't for instance have any counseling system that facilitates those of us dealing with HIV to be debriefed or whatever. So, that is why I actually left the program for a while. I burnt out. I could not cope any longer with the stresses and strain. I totally burnt out.

Government physician

The experience of living in small societies has implications for both the privacy of the patients and physicians' ability to maintain emotional distance from their patients.

As we live in a small country, you do get very close to people. When you walk the streets you see the patients. When you go to church you see them, when you go wherever, it is hard to 'get away from patients' in that way. That's how it is in a small country.

Physician in private practice

Another challenge or consequence of living in small society is the loss of privacy for patients seeking treatment. Some physicians reported delivering medication to patients in their offices so that patients could avoid having to fill their prescriptions at the pharmacy. This courtesy is extended to assist patients who fear they will be identified as being HIV positive if they are seen collecting their medication. There is an attempt to anonymize HIV/AIDS patients in the Eastern Caribbean. Blood tests and prescriptions for antiretrovirals do not include the

patients' name. The name is replaced by a code that is meant to conceal the patients' identity. Even with this assurance, patients still have reservations about whether they will still be identified as being HIV-positive when they show up in person for tests or medication.

But there are still some people who, because all pharmacy staff will change from time to time, will be afraid that they would meet someone who is either related to them or who knows their family. So, in those cases we actually try to help them, sometimes by even picking up their medication and delivering it at the clinic. Rather than have them go to the pharmacy.

Government physician

Discussion

Discussions about the special needs of resource-limited settings have focused more on treatment outcomes and less on the providers of care. Studies have demonstrated pharmaceuticals' effectiveness in emphasizing the ethical imperative and the economic justification for providing treatment to resource-limited venues (Freedberg et al. 2001; von Schoen T. et al. 2001). Early publications about the use of antiretrovirals in Sub-Saharan Africa addressed concerns about whether low-income countries had the infrastructural capacity to maintain continued and reliable delivery of antiretroviral therapy (Harries et al. 2001, Ivers et al. 2005). More recently researchers have sought to demonstrate that treatments outcomes were equally optimistic in these settings as in more developed countries (Desvarieux et al. 2005; Pujades-Rodriguez et al., 2008, Pujades-Rodriguez et al., 2010, Menzies et al. 2011, Calmy & Ford, 2007).

There have been some similarities between the experience of health professionals offering care in remote settings and humanitarian contexts and physicians working in tightly knit, under-resourced contexts like the Eastern Caribbean. These studies which elaborate on the ethics of rationing limited resources, the challenges of knowing people in different contexts (overlapping relationships) and cultural mis-match between the provider and patient (Hurst et al.2005; Schwartz et al. 2010; Pullman & Singleton, 2004). While there were no reported ethical or moral dilemmas around the allocation of medication resources in the Eastern Caribbean, the ethical challenges are more likely be around the issue of partner notification since contact tracing is practiced in the OECS for newly-diagnosed patients. Scholarly discussions on medical ethics in the Caribbean have not focused specifically on HIV/AIDS and notification obligations between sero-discordant couples which is an issue that physicians in this study have encountered (Abell, 2007; Hariharan, S. et al. 2007; Massiah et al. 2004).

Another culturally-influenced aspect of the physicians' response is expressed in their willingness to personally provide occasional cash transfers to economically-disadvantaged patients, or to forego financial remuneration for services provided. These expressions of assistance were favors which physicians provided of their own volition. This generosity is a reflection of the collectivist ethos and low power-distance identified by Hofstede (1980), where Caribbean cultures tend to score high in collectivistic tendencies and low in power-distance orientation (Chioneso, 2008). The Eastern Caribbean +countries share similarities in culture, seen in political histories, idioms, and health system structure which is maintained through traditions of inter-island mobility.

A collectivist orientation suggests that responsibility for well-being extends beyond the individual and is expressed in the community's willingness to extend assistance to an individual

in need. A low power-distance suggests that people of high status do not accept that power should be unequally distributed in the society. This is demonstrated when physicians – professionals of high social status – are willing to go the extra mile to offer support, and also in patients’ willingness to admit directly to their physicians when they do not have enough money to pay. The extent to which this is evident is regulated by physicians’ personal attitudes towards HIV/AIDS. These responses and tendencies are not totally unexpected in “small” societies where people know each other and where social interactions tend to be more frequent. Populations in the OECS countries range from approximately 12,000 in the case of Nevis⁴² to 203,000 in St. Lucia *(St.Kitts/Nevis, In press; World Bank, 2011).

Limitations in health care resources which result in unsatisfactory working conditions are factors known to influence the migration of medical professionals from the Caribbean and other developing countries (Gulliford, 1994; Astor et al, 2005; Bezuidenhout et al. 2009). Increases in psycho-social stress, workload, and in some cases workforce morbidity have been a reality of the human resources response to HIV/AIDS (WHO, 2004). According to the World Health Organization, three OECS countries (St. Vincent & the Grenadines, Grenada and Antigua/Barbuda) are among the top 11 countries in the world with the highest expatriation rates to the industrialized OECD countries (WHO, 2010b). The Caribbean Community (the intergovernmental organization encompassing OECS and other Caribbean countries) has expressed concern about the migration of health professionals from the region (CARICOM, 2007).

⁴² Nevis is the smaller island included in St. Kitts/Nevis whose combined population is 53,051.

Accounts by health professionals in Nigeria and South Africa who lacked the necessary resources, and were initially only able to treat opportunistic infections or reduce patients' discomfort in their final days are comparable to the early experience of Eastern Caribbean physicians (Idoko, 2012; Karim, 2011). It is not unusual for physicians and health systems grappling with the enormity of the disease to devise unusual responses. A physician in Nigeria reported that his hospital would provide sleeping facilities for those who lived an entire day's journey away and were confronted with the prospect of overnight travel after consultations with physicians (Idoko, 2012). In South Africa, health-care providers' empathy towards patients was rooted in a perception of their own vulnerability to the disease (Stein, 2007).

Just as economic constraints influence the ability to provide the tangible components of care, stigma has a pervasive influence on the conditions in which care is provided and the delivery and uptake of health services. Stigmatizing attitudes about HIV/AIDS are also perpetuated among Caribbean health professionals among whom there was a self-reported tendency to distance themselves from patients, blame patients for their illness and disclose patients' HIV status to colleagues for non-medical reasons (Abell, 2007; Andrewin, & Chien, 2008, Massiah et al. 2004). These attitudes were predictably absent from the physicians in this study. However, physicians who treat this group of patients are subject to global prejudices directed towards people living with HIV because of assumptions about the disease (Snyder et al., 1999; Herek, 1999). This "secondary stigma" or "courtesy stigma" directed towards people who do not themselves have the disease, but who are associated with patients, reduces caregivers' sense of well-being and likelihood of continuing to work with this group of patients (Herek et al. 1998; Bredfeldt, 1991).

Stigma is expressed within local power, cultural and social contexts (Parker & Addeilton, 2003). The stigma and discrimination from which physicians try to shield their patients by offering services in their private offices is a credible social phenomenon for people living with HIV. In a survey that included three Eastern Caribbean countries, key informants who were HIV positive revealed verbal and other forms of abuse, avoidant behavior, threats of arrest or deportation, and exclusion from social interaction and employment (Royes, 2007). The survey also found the main perpetrators of stigma and discrimination were: family, someone known to the person with HIV/AIDS, young people, specific health workers, individuals in the school environment, the workplace or general public. A study in another Caribbean country – Jamaica includes accounts of people with HIV whose HIV test results were divulged to the community by hospital workers and who see secrecy about their HIV status as a way of avoiding discrimination Carr (2002).

Summary

Physicians in the Eastern Caribbean treating HIV/AIDS patients recognize that they could “only able to work with what [they] have”, and have reported feelings of frustration in recognizing that patient-needs sometimes exceed local health system capacity. The economic environment and cultural context (including stigma and discrimination) have a ubiquitous influence on the practice of medicine. Physicians are firstly constrained by the availability of resources which restricts their prescribing options in second-line and third-line antiretrovirals and the range of monitoring tests which can be performed on patients. Secondly the cultural environment which is predominantly a collectivist orientation and characterized by low power-distance in tightly networked societies allow physicians to empathize and identify with patients.

In the Eastern Caribbean physicians' ability to treat HIV/AIDS patients is influenced by the medical resources at their disposal, the socio-cultural context in which they practice, the pervasive stigma associated with the disease and how they see themselves in relation to these determinants.

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Introduction to Chapter 6

This chapter is a paper titled, “Calculating the Affordability of Antiretrovirals in St. Lucia,” which zeroes in on the affordability aspect of universal health coverage, and specifically on the affordability of medication. This paper engages only one of the five countries from the previous paper. Data was not available from the other countries due to legal and policy restrictions that prohibit the sharing of household survey data with researchers who are not affiliated with the respective governments.

In this paper, different standards of affordability are employed because there is no single, compelling way to quantitatively define affordability. Therefore, the paper proposes several methods that fall into the categories of impoverishing expenditure (being forced to live below a particular poverty line due to the cost of medication) and catastrophic expenditure (spending more than a certain amount of one’s income on medication). This point and the approach to establishing catastrophic expenditure was later affirmed by the Inter-Agency Expert Group on Sustainable Development Indicators (IEAG SDG). The IEAG SDG eventually proposed two thresholds: 10% and 25% of total household consumption (or income) (Sustainable Development Goals Knowledge Platform, 2018). The following chapter considers the national poverty line—10% of annual consumption, 50% of median annual consumption—and proposes a *reasonable minimum* standard. The paper is presented as evidence for the need for financial protection to cover the cost of medication if people living with HIV in St. Lucia are to attain universal health coverage.

Chapter 6: Calculating the affordability of antiretrovirals in St. Lucia

JR Reddock & M Grignon

Abstract

The cost of antiretrovirals is borne by donors in many low-and-middle-income countries, including St Lucia. Although donor involvement has facilitated access to antiretrovirals, donor engagement in HIV/AIDS has changed over the years. This paper assesses the affordability of antiretrovirals at the individual level if donors were no longer available to fund the cost of first and second-line antiretrovirals and a prospective third-line regimen. Various conceptions of affordability are reviewed using different assumptions of what is required to maintain a standard of living that would avoid individuals descending into poverty as a result of antiretroviral purchases. These concepts of affordability are operationalized using data from the Household Budgeting Survey conducted in St Lucia in 2005/2006. While there are a range of results for the affordability of first and second-line antiretrovirals depending on which standards of affordability is used, third-line antiretrovirals are unaffordable to more than 80% of the population across the four standards of affordability used – the national poverty line, 50% of median annual consumption, 10% of annual consumption and a proposed reasonable minimum standard.

Introduction

The cost of antiretrovirals is the most expensive factor in the treatment of HIV/AIDS patients and is mostly covered by donor funding to St. Lucia and the other countries in Eastern Caribbean (1),(2). For several years after the first HIV case was reported in 1984, none of the

countries could afford to provide antiretrovirals to HIV/AIDS patients in public programs (3). As a result, very few patients in the Eastern Caribbean were able to access antiretroviral therapy.

In February 2005, St. Lucia and the other countries in the Organization of Eastern Caribbean States⁴³ received the first disbursement from the Global Fund to purchase first-and-second-line antiretrovirals under a multi-country grant of US\$8 million (4). The Global Fund later provided around US\$2.5M from 2008 to 2012 (5). St. Lucia obtains antiretrovirals through a pooled procurement system with the other OECS countries which is more cost-effective than if prices were negotiated by countries separately (6).

In a recent study, the OECS countries were assessed as highly dependent on external financing for antiretroviral therapy (7). This emphasis on donor funding leaves countries vulnerable to changes in the donor environment. Donor contributions to the Global Fund declined for the first time in 2010 after showing steady increases since 2002 (8). The 2008/2009 financial downturn and donor fatigue resulted in donors shifting their attention away from HIV/AIDS (8),(9),(10). There is currently no private health insurance offered to HIV/AIDS patients, and by World Bank estimates individuals in St. Lucia generally cover 98.8% of their out-of-pocket costs from 2008 to 2012 (11). An evaluation of the capacity to pay is one way of assessing the likelihood of the catastrophic impact of antiretroviral purchases.

This study explores the potential ability of individuals to pay for antiretrovirals if donor or government assistance is no longer available. This paper discusses various approaches to conceptualizing affordability of health care and the assumptions underlying these perspectives

⁴³ The six OECS countries benefiting from The Global Fund grant are Antigua/Barbuda, Dominica, Grenada, St. Kitts/Nevis, St. Lucia and St. Vincent and the Grenadines.

and addresses what proportion of the population would be unable to afford first, second and third-line antiretrovirals using household budgetary data from St. Lucia.

This paper proposes a threshold which is here called “the reasonable minimum approach”. This standard of affordability” establishes food, clothing, shelter and transportation as necessary for subsistence, and proposes that in order for antiretrovirals to be affordable, they should not constitute more than 40% of an individual’s remaining budget once these subsistence needs are met.

Review of Methods

Affordability is one of three factors in the accessibility of health care – where the other two components are availability and acceptability (12). A treatment or health intervention is available if it is offered and is within reach of the patient without barriers or restrictions (13). The acceptability dimension is satisfied if the patient and the provider share the view about the efficacy of the treatment, and if care is delivered in conditions amenable to the patient (14),(12). A treatment is not affordable if patients do not have the ability to pay for it either from their own income, credit arrangements or health insurance (15). The three components of access (affordability, availability and acceptability are relevant to the equity and efficiency of health systems (16),(17),(18).

In addition to antiretrovirals being available and acceptable to patients in St. Lucia, this paper affirms the premise that antiretrovirals are necessary to prolong and enhance the quality of life for patients with HIV and that the ultimate consequence of unaffordable antiretrovirals is death (19),(20). For people who are already socio-economically disadvantaged and have neither savings nor health insurance to cover out-of-pocket expenses, HIV/AIDS triggers a health-

poverty trap if their income does not allow them to maintain an adequate standard of living while meeting health-related expenses (21). A disease (such as HIV/AIDS) with premature mortality and high morbidity is likely to have high productivity losses in the working age population which would subsequently have a catastrophic impact because of the resulting inability of the household to maintain the customary standards of living (22). Direct health care costs after being diagnosed with HIV/AIDS – including out-of-pocket costs for medication worsens the financial situation of the already poor and for others initiates a downward spiral into poverty initiated by increased allocations of income on health care expenditure, sale of household assets or depletion of personal savings (23), (24). Russell defines HIV/AIDS-related impoverishment is “household asset depletion and income loss that cause consumption levels to fall below minimum needs” (p. 147) (25). In the absence of insurance coverage to alleviate the economic burden, government-sponsored treatment softens the economic impact by removing the need for patients’ out-of-pocket costs for pharmaceutical purchases (26). For both high and low-income individuals expenditure for antiretrovirals are involuntary, unanticipated and require a life-time of medication since there is no cure.

Affordability is characterized relative to an individual’s ability to pay. By the most stringent definition, a treatment is unaffordable if exceeds a person’s budget, or if an individual’s entire earnings has to go towards that treatment. However, this definition of affordability is too restrictive. Although the possibility of death conveys the priority of obtaining this treatment, all income cannot be allocated to medication because there are other life-sustaining expenditure that a person must incur (for example food) to be able to survive. Therefore antiretrovirals cannot and should not constitute 100% of the budget. A further consideration of affordability considers what standard of living people aspire to maintain – which is a normative choice with an almost infinite

number of possibilities (27). Several ways of defining an adequate standard of living and are applied in the empirical section of this paper.

A specific health purchase is affordable if there is enough income after the purchase to meet other socially-determined minimum needs (28). Some health economists use the term “catastrophic”, “impoverishing” or “excessive” to describe medical expenditure that prevent a family (or individual) from maintaining its customary standard of living (22),(29),(30). Three concurrent conditions lead to catastrophic health expenditures – (i) health services that require out-of-pocket payments, (ii) low household capacity to pay and (iii) the absence of pre-payment mechanisms for risk pooling (31).

When introduced in absolute terms, that acceptable standard of living which differentiates the poor from the non-poor can be determined by poverty lines that are either globally recognized or nationally-established. Neither of these two standards is without critics. National poverty lines are said to underestimate local poverty for political purposes (32). The World Bank’s poverty line (originally set at US\$1.00 per day) has been critiqued for being too low for middle-income countries and for being based on unrealistic living standards (33). In 2008, there were upward revisions of the global poverty lines to US\$1.25 for extreme poverty and US\$2.00 for developing countries, and a further proposition that \$4.00 per day standard was being more acceptable for Latin America and the Caribbean (34),(35),(36). On the basis of a Gross National Income per capita (using the Atlas Method⁴⁴) of US\$6530, St. Lucia is classified as a middle-income country (36) (37).

⁴⁴ GNI per capita is calculated using the Atlas method. “The Atlas conversion factor for any year is the average of a country’s exchange rate (or alternative conversion factor) for that year and its exchange rates for the two preceding years, adjusted for the difference between the rate of inflation in the country, and through 2000, that in the G-5 countries (France, Germany, Japan, the United Kingdom, and the United States). For 2001 onwards,

The 2005 official poverty line in St. Lucia of EC\$5,086 (US\$ 1,904.87) per annum is obtained using the cost of basic needs which is derived from a food-poverty line, which is then adjusted upwards by the non-food component(37). The non-food component is obtained by taking the average non-food consumption of the adult equivalent expenditure of the bottom two quintiles of the population (38),(39). The food-poverty line, also referred to as the indigence line, is the minimum amount of money required to purchase a nutritionally-balanced diet that provide the daily caloric requirement for a household (37). The caloric requirements are computed by creating a recommended food basket which is obtained by the FOODPROG software of the Caribbean Food and Nutrition Institute which also computes prices of locally-available food (37), (40).

Efforts to address the issue of unrepresentative poverty cut-offs have included using the wage of the lowest-paid unskilled government worker or the average income of a farmer in farming communities. Although these wage-based standards might be less abstract than the poverty lines established for policy and statistical purposes, salaries of government workers for example, might over-estimate the poverty cut-off where civil servants earn more than low-income workers in other industries like tourism or other service industries.

A relative (rather than absolute) approach to poverty has been proposed in an effort to further standardize determinations of poverty. Proponents of this measure advocate using 50% of median income or consumption to establish what level of wealth or poverty would be acceptable.

these countries include the Euro Zone, Japan, the United Kingdom, and the United States." Available at <http://data.worldbank.org/about/country-classifications/world-bank-atlas-method>

Half of the median annual consumption in the survey is EC\$ 4447.96 Some critics say of this median approach that there is no clear basis for taking 50% of income (or consumption) as optimal – since it is based on an assumption that that the mid-point of consumption or earning is optimal relative to higher or lower levels (41) (49).

Others have set thresholds of 5, 10, 15, 20 % of income (22), (42),(43). These percentage-based approaches require the application of a standard that has been admitted to be normative even among authors who have used this approach (29). Also, introducing a specific annual income or consumption target which might seem average by national standards can be economically catastrophic to low-income households (42).

To address the disproportionate impact of percentage-based thresholds, others have introduced the concept of discretionary budget – sometimes called capacity to pay – which is what is left once basic food needs are covered. The non-subsistence portion of the budget is what is used to evaluate affordability – using the idea is that this discretionary budget is now such that room can be made to pay for the drug. Authors recommending the discretionary budget approach use a much higher threshold (around 40% of capacity to pay) but, this is out of a smaller portion of the budget (44).

Applications of affordability to health care goods and services

Xu et al. (2003) estimated the percentage of households in 59 countries in Europe, North America, Asia and Africa where catastrophic health expenditure was defined as 40% of income remaining after basic [food] subsistence needs were met (45). Subsistence expenditure adjusted for household size was taken as the median food expenditure for the 45th to 55th percentile, recognizing the fact that poorer households spend more of their income on food. The health

expenditures were out-of-pocket costs for consultation fees, purchases of medication and hospital bills. A multiple regression across the 59 countries revealed that out-of-pocket payments were the main factor explaining the likelihood of catastrophic expenditures. Other significant variables considered which were not as strongly associated were total health expenditure share of GDP and percentage of households below poverty line.

In a study of 30 countries in Africa, the Americas, Eastern Mediterranean, European Union, South East Asia and Western Pacific Regions, Gelders et al. (2006) applied survey methodology used by the World Health Organization/Health Action International (WHO/HAI) where, the daily wage of the lowest paid unskilled government worker in each country is used as the standard of affordability (46). Prices of medication were gathered from pharmacies in the private and public sectors and non-governmental organizations. WHO/HAI assessed the affordability of medicines as the number of days the lowest paid unskilled government worker would have to work in order to afford to purchase 30 days of treatment a chronic condition. These conditions included in the survey were asthma, diabetes, epilepsy, hypertension and psychiatric disorders.

Using data collected from public hospitals and private pharmacies in Hubei Province, China, Yang et al. (2009) evaluated the availability and affordability of generic and originator versions of 39 essential medicines used to treat the most prevalent diseases based global and local disease burden (47). The medicines were for cardiovascular diseases, diabetes, asthma, respiratory tract infections and mental illness. Availability was determined based on the percentage of medicines in stock. The authors used three standards for evaluating affordability – (i) the Median Price Ratio – a ratio comparing the medicine's local unit procurement and retail prices in the private and public sectors with the international reference price; (ii) the number of

days wage required to treat an acute condition for seven days and a chronic condition for 30 days using the income level of (a) the national poverty line and (b) the per capita net income of a farmer living in Hubei province. Gelders (2006) applied the WHO/HAI standard where a median price ratio of six was an indication of unaffordability, and twice the international reference price for a generic equivalent product and more than one day's wage at either income level was seen as unaffordable (46).

A nationally-representative sample of 14,615 families in the United States about health services utilization, expenditures, health status, and socioeconomic characteristics, found that about one of every five, had out-of-pocket expenditures of at least 5 percent (or more) of their income and almost half of those families incurred out-of-pocket medical care expenditures that were 10 percent or more of their income (22).

Methodology

Prices of first and second-line antiretrovirals used in St. Lucia were obtained from the OECS Pharmaceutical Procurement Services in EC dollars. The procurement price included insurance and freight. The required 10% customs duty charge was added to the procurement price. The annual cost of each drug was calculated using the recommended dosages for adults. The most frequently-used first-and second-line regimens were obtained using data about physicians' prescribing patterns obtained from the OECS Pharmaceutical Procurement Services (**See Box**). Since there are no patients currently on a third-line regimen, the third-line combination recommended by the World Health Organization was used. For the third-line regimen, prospective procurement prices of Raltegravir and Duranavir were obtained from OECS PPS and prices for Ritonavir and Etravirine were obtained from The Global Fund Price

and Quality Reporting where 2012 prices for Jamaica (a Caribbean Upper Middle-Income country included in the Global Fund price reports were used). It is possible that OECS PPS might negotiate prices different from those for Jamaica. However, the quoted prices from Jamaica for Ritonavir and Etravirine were used as an approximate estimate for what St. Lucia would be charged as an upper-middle-income country under differentiated pricing arrangements.

Consumption data is used as proxy for income in the Caribbean where there tends to be under-reporting of income by respondents; the substitution can also be applied when consumption is a more accurate representation of actual living expenses among seasonal workers and for individuals including the very poor who rely on gifts to meet daily expenses (39)(41). Expenditure rather than income is a better reflection of resources since it more accurately measures what an individual actually consumes, whereas income might under-estimate the resources an individual uses because it fails to capture what is supplied as donations by friends or family. In developing countries with a large informal sector, survey respondents may not want to reveal their true income (48).

Total annual consumption of adult individuals was obtained from St. Lucia's Household budgetary survey which was conducted from September 2005 to March 2006. The survey is the most recent source of information on national consumption patterns. Consumption figures were adjusted to 2012 values by applying the Consumer Price Index obtained from St. Lucia's Statistics Division and the Eastern Caribbean Central Bank. The July 2012 annual cost of first, second and third-line antiretrovirals was subtracted from the annual consumption of individuals in the survey. **See Box 1**

First-line regimes are provided to patients when they are initially diagnosed – which is usually a three-drug combination of antiretrovirals – one from each category of Nucleoside

Reverse Transcriptase Inhibitors, Non-Nucleoside Reverse Transcriptase Inhibitors and Protease Inhibitors (49). Typically, second and third-line regimens are constructed based on the patient's medical history, the selection of drugs available when patients initiated treatment, and the co-morbidities or opportunistic infections which are present. If a patient develops resistance to first-line antiretrovirals, they are advanced to second-line antiretrovirals and ultimately to third-line. OECS and World Health Organization treatment guidelines indicate which drugs are recommended for different stages of the disease progression.

First-line regimen: Lamivudine + Nevirapine + Zidovudine	⁴⁵ EC\$301.64
Second-line regimen: Tenofovir + Lamivudine + Lopinavir-ritonavir	EC\$1036.80
Third-line regimen : Raltegravir+ Darunavir-r +Etravirine	EC\$16275.8

Box 1: Annual Antiretroviral regimens and prices

This paper applies four conceptual approaches to assess the affordability of the most frequently-prescribed antiretrovirals. Three of these approaches have been discussed in earlier sections (a national poverty-line, a median poverty-line and two percentage-based thresholds). The World Bank's extreme and adjusted poverty lines were not considered because that standard would not be below the national poverty lines which have been set based on empirical standards. The lowest paid government worker standard was not used because of reasons stated above. The 10% of annual consumption threshold is used as a comparator in preference to the other levels as

⁴⁵ US1\$ = EC\$2.70

it is supported by research showing that almost half of families who spend 10 percent or more of income on medical care are at or below the poverty level (22).

Prices of each of the first, second and third-line regimens were subtracted from annual consumption of individuals in the dataset. After the prices included in the annual consumption, an indicator variable was assigned to individuals (i) whose total consumption was below the government poverty line after purchase of the first, second, and third-line regimen (ii) whose total consumption was below 50% of the median consumption after purchase of the first, second, and third-line regimen (iii) for whom the cost of first, second, and third-line regimens constituted more than 10% of total consumption (iv) for whom the cost of first, second, and third-line regimens constituted more than 40% of non-subsistence consumption.

The fourth standard of affordability is based on an observation by Ravallion (1992) that “[p]overty’ can be said to exist in a given society when one or more persons do not attain a level of material well-being deemed to constitute a reasonable minimum by the standards of that society” (p. 4) (34). If food, clothing, shelter and transportation are considered to be reasonable and minimum requirements necessary for subsistence, antiretrovirals are affordable if they constitute 40% of the budget remaining after expenses for these basic necessities are met. Annual food costs were determined by the government established food poverty (indigence line) discussed above. Median transportation, clothing and housing costs were obtained from consumption reported in the data. Forty percent is admittedly an arbitrary figure which is meant to represent less than half of non-subsistence expenditure.

Results

_____By various standards of affordability, first-line antiretrovirals are unaffordable to at least 7% of the population, second-line antiretrovirals are unaffordable to at least 23% of the population, and third-line antiretrovirals are unaffordable to at least 84% of the population. (See **Table 1**). The results from all scenarios suggest that a third-line regimen is unaffordable to almost all St. Lucians using all standards of unaffordability. Since the antiretrovirals comprising the WHO-recommended third-line treatment comprise three drugs which are still under patent, there are no cheaper generic versions available. Under the Trade-Related Aspects of Intellectual Property Rights, cheaper generics cannot be available until the patents expire – which in the case of Raltegravir, Darunavir will be in 2025, and Etravirine in 2019 (50). Patents were extended beyond the initial 20 years after the initial patent applications because of “evergreening” by pharmaceutical companies – a practice where manufacturers extend the patent by demonstrating (or claiming) that an updated version of the drug is available as a result of scientific innovation by the manufacturer’s researchers.

	National Poverty line*	50% of Median annual consumption**	10% of annual consumption	Reasonable minimum
First-line regimen	30% (+1.2%)	17.1% (+3%)	7.4%	73.4%
Second-line regimen	36.8% (+8%)	23.4% (+9.3%)	63.8%	77.6%
Third-line regimen	86.9% (+58.1%)	84.8% (+70.7%)	100%	98.1%

*Percentage of the population below the national poverty line before purchase: 28.8%.

**Percentage of the population below 50% of median annual consumption before purchase:
14.1%

Numbers in brackets reflect the percentage change in proportion of the population
impoverished after purchase of antiretrovirals

Table 1: Percentage impoverished by antiretroviral purchases at various thresholds

The national poverty line offers the most stringent definition of affordability and by based on the consumption patterns of the least affluent 40% of the population. The reasonable minimum standard is not as stringent as others cited and deliberately allows for greater discretionary spending. The median approach offers an assessment of poverty based on consumption patterns in a relative sense, but does not offer any real insight into the standard of living enjoyed by individuals. The percentage-based standard of affordability is the most arbitrary approach where 10% is the most widely-used standard in affordability studies (29),(43) .

Discussion

In 2004, before the initiation of The Global Fund grant, St. Lucia received a World Bank loan of US\$6.4 million to introduce antiretroviral treatment, support government, community and civil society initiatives, health system strengthening and capacity building (51), (52). The Global Fund’s proposed new funding model⁴⁶ and suspension of the annual call for proposals in 2011 because of concerns about the sustainability of funding suggest a change in operational policies (53). Recent Global Fund eligibility criteria require upper-middle-income countries to be

⁴⁶ The New Funding Model will be implemented in late 2013 after finalization of funding for the 2014-2016 cycle. See http://www.theglobalfund.org/Documents/core/newfundingmodel/Core_NewFundingModel_Overview_en/

evaluated based on their respective disease burden and to provide 60% counterpart (cost-sharing) financing for future Global Fund projects (54),(55). These events signal a need for the re-examination of the affordability of antiretrovirals and an assessment of the potential economic impact of antiretroviral purchases at the individual level in the event that donor or government assistance were not unavailable.

Global health initiatives like (like PEPFAR and The Global Fund) were established to improve the availability of antiretrovirals in developing countries (56), (57). The 2002 Accelerated Access Initiative (AAI) brokered by the World Health Organization allowed pharmaceutical companies to institute differentiated pricing arrangements for low-and-middle-income countries in the Caribbean and Africa. The lowering of prices, through AAI and the emergence of The Global Fund as a leading resource-mobilization entity for HIV/AIDS and other diseases, countries facilitated the provision of antiretroviral therapy at no cost to patients in the public system.

Affordability is an ambiguous concept since it involves normative decisions at the household or individual level (58). Defining affordability of medicines or any other commodity is moot issue because it relies on definitions of poverty which are governed by various methodological and ideological definitions (41). The ability to maintain a customary or socially-acceptable standard living is an important component of the concept of affordability. By establishing median consumption levels of clothing and housing expenses as acceptable, individuals have a relatively satisfactory level of well-being compared with others. Unlike the subsistence method proposed by Murray and colleagues which incorporates only food expenses (44), the reasonable minimum standard incorporates other necessarily consumption – namely food, clothing, shelter and transportation. Under the proposed reasonable minimum standard

there is ample room for other discretionary spending since this approach to affordability leaves 60 percent for other spending after antiretroviral purchases. The inability of HIV/AIDS patients to obtain health insurance to cover the cost of antiretrovirals might be linked to the pervasive stigma associated with the disease. Policy changes in the insurance industry that allow coverage for HIV-positive patients would alleviate concerns about possibilities for financing antiretroviral care.

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Chapter 7: Summary of Results and Implications of Research

This dissertation studies universal access to health care after a discussion of the conceptualization and measurement of universal health coverage (presented in Chapters 2 and 3). Studying the process of selecting indicators for evaluating progress towards universal health coverage in the Sustainable Development Goals (SDGs) presents a view of the global policy-making process where different interest groups are represented. The first two papers addressed the conceptualization and measurement of universal health coverage—specifically information about the indicator selection process and generalized guidance for evaluation.

The Inter Agency Expert Group on Sustainable Development Goal Indicators (IAEG SDG) responded to criticism about the opacity of the indicator selection process by opening up the deliberations to a variety of stakeholders. As discussed in Chapter 2, the compromises and increased engagement that are features of multi-stakeholder discussions were evident in the proceedings of the IAEG SDG. The two lead agencies for the universal health coverage indicators—the World Bank, which represents economic development perspectives, and the World Health Organization (WHO), which represents health perspectives—were eventually successful in their lobbying for an indicator measuring coverage of essential health services. However, both agencies eventually had to compromise on the issue of a financial protection indicator, ultimately selecting one for catastrophic expenditure but not for impoverishing expenditure.

Chapter 5 investigates how physicians provide treatment and care for people living with HIV in Antigua and Barbuda, Dominica, Grenada, St. Kitts and Nevis, St. Lucia, and St. Vincent and the Grenadines. Chapter 6 empirically addresses the issue of financial protection, specifically in the case of HIV treatment in St Lucia, and shows that impoverishing and catastrophic

expenditures can yield dramatically different pictures of affordability. Being able to measure impoverishing expenditure based on a poverty line offers a more reliable and conceptually compelling indication of the potential financial impact of out-of-pocket expenditure on health care than do indicators of catastrophic expenditures. Of course, national poverty lines are themselves somewhat arbitrary and there is no single measurement of poverty. However, assuming there is agreement on a poverty line, suggesting the minimum level of expenditures below which one cannot live a meaningful life—an impoverishing expenditure indicator—provides an objective measure of non-affordability. In contrast, catastrophic expenditure indicators rely on unverifiable assumptions of how households spend their income and arbitrary assumptions of what constitutes catastrophic spending. The ways of determining catastrophic expenditure seem more arbitrary than determining the poverty line since there is no standardized way of determining what percentage of income or consumption dedicated to health care is excessive or whether people are able to meet a particular benchmark of subsistence.

Chapter 5 reveals physicians' prior experience with antiretrovirals being historically unaffordable except to the wealthy, and the governments' current stance on not covering the cost of third-line antiretrovirals (on account of them being too costly), but opting to pay for first- and second-line antiretrovirals. The analysis in Chapter 6 lends credence to observations about the general unaffordability of antiretrovirals and particularly third-line medication that might be attributed to St. Lucia that was expressed through the qualitative results in Chapter 5. The paper was pursued in line with the concept of complementarity in mixed methods research, where the broader question was "How widespread is the issue of unaffordability of antiretrovirals for people living with HIV in the OECS? The data guided an approach more in-line with complementarity rather than triangulation in integrating the results from the two empirical

papers. Complementarity is understood as “[a]n argument for using mixed methods to obtain more complete conclusions by using quantitative and qualitative methods to get complementary results about different facets of a phenomenon” while triangulation is “[a]n argument for using mixed methods to obtain more valid conclusions about a phenomenon by directly comparing the results obtained from quantitative methods to those obtained from qualitative methods for convergence and divergence” (Plano Clark & Ivankova, 2017, Chapter 4).

Because quantitative data was available for St. Lucia (one of the countries) and because income data was not available for people receiving free antiretrovirals, the exactitude that is obtained through triangulation could not be obtained. The results indicate that by different standards of affordability, there were undeniably notable segments of the population who would potentially not be able to afford antiretrovirals if they needed it. The results from Chapter 6 add another perspective to the findings of Chapter 5 about the unaffordability of antiretrovirals by providing a complementary perspective of how widespread the phenomenon of unaffordable antiretrovirals could be and raising potential questions such as: If the government does not purchase third-line antiretrovirals in St. Lucia, what proportion of the adult population could afford to purchase this medication as an out-of-pocket payment, if they needed to? The answer demonstrates that even with various definitions of affordability (through impoverishing or catastrophic expenditure), there were not wide swathes of the population who would not encounter some degree of financial hardship as a result. The results in Chapter 6 complement the results in Chapter 5 by showing that by any of the four standards of poverty (the national poverty line, 50% of annual consumption, 10% of annual consumption, and a reasonable minimum standard), any purchase of antiretrovirals would cause some proportion of the population to be impoverished. From 14.1% to 28.8% of the adult population in St. Lucia were already too

impoverished to even purchase antiretrovirals. Anywhere from 7.4% to 100% of the population would be impoverished by potential purchases of antiretrovirals. This adds credibility to the observations of physicians in the six countries (including those in St. Lucia) that antiretrovirals were unaffordable to the clients they treated from different economic backgrounds.

Precise indicators are useful for both monitoring and evaluating universal health coverage. The importance of multi-stakeholder perspectives for evaluations is affirmed in Chapter 3, where it is shown that the perspectives and priorities of the consumers of health care are different from those providing it. Regarding health care, although there are differences in perspectives and priorities between those providing health care and those utilizing health care, both groups provide the needed diversity for effective evaluations. Chapter 3 recommends participatory evaluations for universal health coverage that would include those involved in delivering care and formulating policy (on the supply side), as well as those receiving care (on the demand side).

The real test of global health policy occurs during the implementation phase. In Chapter 5, the focus of the paper is physicians in the Eastern Caribbean which therefore provides a perspective of the impact of global policies within this group. Focusing on physicians who treat people living with HIV also provides insight into the human resources element that is vital for attaining universal health coverage. During the study, physicians indicated that resource limitations impeded their ability to provide the levels of care they would have wanted to make available to people living with HIV. Physicians revealed that, in some cases, it was not unusual for them to use their own resources to help fill the resource gaps. Resource limitations, such as unaffordable third-line antiretroviral drugs (ARV), limit the ability to provide the best levels of access to care. Since financial protection was not available to people living with HIV, Chapter 5

provides a descriptive justification for universal health coverage (while Chapter 6 provides quantitative evidence).

The findings in Chapter 5 reinforce the multi-dimensional aspect of access on which universal health coverage relies. From the physicians' perspective, resources for treatment and testing needed to be available and affordable—specifically third-line antiretrovirals and viral load tests. Also, health facilities had to be acceptable in terms of assuring privacy to people living with HIV and needed to be located within geographical proximity. Services also needed to be offered at convenient times, not just during the traditional eight-hour business day.

The availability of free ARVs at public facilities (the shortage of testing facilities notwithstanding) with limited attention to the acceptability component exposes the fissures in the Millennium Development Goal (MDG) approach to access as the emphasis was on affordability and availability but not on acceptability. Although physicians' services and some ARVs were available and affordable (to the extent that there were policies in place to reduce the need for out-of-pocket expenditure), the delivery systems did not ensure acceptability in terms of the privacy needs of people living with HIV

Apart from the importance of the diversity of perspectives and priorities is a recognition of the uniqueness of policy implementation sites. Although some of the countries in the study sample are high-income and upper-middle-income countries, the on-the-ground implementation of the commitment to universal access to treatment and care for HIV shows that gross domestic product (GDP), which determines income classification, is not the determining factor in the ability to provide access to health care and universal health coverage.

While Chapter 5 makes the case for a precise implementation of universal access that aligns with the components of universal health coverage, Chapter 6 demonstrates some of the

reasons why the financial protection component of universal health coverage is important. The results showed that, by various standards of affordability, many people in St. Lucia would not be able to afford third-line ARVs. The results of this paper show the magnitude of the affordability problem in St. Lucia. Fifty-eight to seventy-one percent (58% to 71%) of residents would become poor if they had to buy the third-line regimen of care, and all of them would have to spend at least 10% of their income on it.

Direct Implications from the Research

Increase Government Allocations for Health

Many of the changes that advance universal health coverage will require increased resources and public financing for health. Despite the best intentions, the ongoing challenge of funding necessary health care spending for resource-poor countries will not be solved by simply introducing universal health coverage. The financial vulnerability of some people living with HIV (discussed in Chapter 5) and the unaffordability of ARVs (discussed in Chapter 6) and the fact that antiretrovirals had to be made available in the public system at no cost because health insurance was not offered to people living with HIV demonstrate a need for financial protection provided by the health sector. Recommendations such as expanding the tax base (with the caveat that taxes should be progressive) can be implemented based on the fiscal realities in individual countries (Heller, 2006). Policy-makers have other options such as pursuing overall economic expansion, cost sharing/private financing, seeking external resources, resource shifting, community health financing, social insurance, and improved governance (Durairaj & Evans, 2010).

The governments of the six countries in the study and all other Pan American Health Organization (PAHO) Member States have agreed that 6% of GDP would be the allocation benchmark, with priority going to meeting primary-level health care needs (PAHO, 2014). The latest information on governments' contributions to health care (from the year 2015) suggested that they had not yet reached the agreed level of spending. As of 2015, total current expenditure on health care goods and services (excluding capital expenditure and emergency stocks of vaccines) was as follows: Antigua and Barbuda, 4.84%; Dominica, 5.43%; Grenada, 5.0%; St. Kitts and Nevis, 5.62%; St. Lucia, 5.96%; and St. Vincent and the Grenadines, 4.21% (World Bank, n.d.-a, World Bank, n.d.-b; WHO, n.d.).

Financial Protection for Accessing Health Care.

The absence of health insurance for people living with HIV makes the provision of free treatment and care in the public health system even more necessary. Health insurance should be made available in a non-discriminatory way. Discrimination in insurance, where coverage is denied to people living with HIV, runs counter to the right to health. Two countries, Antigua and Dominica, already have social insurance in place. However, care must be taken to ensure that financial protection in the form of health insurance is not extended to only civil servants.

Policies for Retention of Skilled Health Professionals

The potential for burnout and stress among health service providers that was revealed in Chapter 5 should not be ignored. Some of this stress is associated with working without adequate health technologies (Delobelle et al., 2011). The appropriate mental health supports should be in place to support the management of workplace stressors that health professionals encounter. The global shortage of skilled health professionals results in the *pull factors* that lead to migration of professionals to countries with higher wages and other incentives for health professionals

(Grignon et al., 2013). Furthermore, the prospect of working with desirable health technology can also be a factor in migration decisions. While respecting personal autonomy, workplace and human resources policies to support the retention of skilled professionals for HIV, and for universal health coverage in general, are recommended.

Governments should be responsive to human resources concerns and work to ensure that professionals have the resources they need to work effectively. As noted in Chapter 5, a shortage of health technology can have a negative effect on the morale of health professionals. Working in a poorly-resourced environment can lead to high staff turnover (Delobelle, et al., 2011). Antigua, Grenada, Dominica, and St. Vincent and the Grenadines have been cited among countries with more than half of native-born health professionals living in other countries (United Nations Department of Economic and Social Affairs, 2010). The PAHO launched a study on the migration of Caribbean health workers to update these estimates. The results were originally to be available in 2018⁴⁷.

Availability of Services

As demonstrated in Chapter 5, most non-emergency physician services for routine tests and appointments are available only on weekdays during the designated eight business hours of the day. Expanded hours of availability in the public sector would increase the availability options to those seeking care (National Health Service, 2013).

⁴⁷ As of July 8, 2019, a response from PAHO public affairs: “We have no updates to share on the report at this time. We don’t know yet when it will be finalized and available.”

Attention to Social Determinants of Health and Interconnectedness of the SDGs

Chapter 5 revealed the effect of the absence of a social safety net to provide food and other basic requirements for people in the lowest income brackets. The linkages among the SDGs is cited as important to the success of the entire 2030 Agenda for Sustainable Development (the 17 SDGs that address cross-cutting issues including environmental protection, poverty reduction, and justice, among other issues). Research on the social determinants of health documents shows that people who lack the basic requirements for living and who are vulnerable are more susceptible to disease, have greater difficulty getting necessary health care and recovering from illness (Wilkinson & Marmot, 2003).

Indirect Implications of the Research Based on the Papers in the Dissertation

Governments' Obligations to Respect, Protect, and Fulfill the Right to Health

HIV care is an essential aspect of universal health coverage and is included as one of the tracer indicators for universal health coverage. As discussed in the Introduction, lessons learned from HIV can be instructive to the wider effort to attain universal health coverage. The lack of capacity to respond to HIV in the 1980s was replaced by a wider global health effort that included assistance from international development partners and governments' prioritization to implement a more robust HIV response. Even with limited resources, governments are expected to seek international cooperation and assistance from international partnerships to ensure that residents fully realize the right to health (Office of the United Nations High Commissioner for Human Rights, World Health Organization, 2008).

Governments have a responsibility to advance human rights and the right to health. Universal health coverage fully supports the human right to health and the Universal Declaration

of Human Rights (that asserts that “[e]veryone has the right to a standard of living adequate for the health and well-being of himself and of his family” (article 25). Although none of the six countries in the study provide constitutional protection for the human right to health (and only Dominica, Grenada, and St. Vincent and the Grenadines have acceded to the International Covenant on Economic, Social, and Cultural Rights, which specifically mentions the right to health), all of the countries are party to at least two human rights treaties that affirm the right to health (Cenac, 2010, United Nations Human Rights Office of the High Commissioners, n.d.). Therefore, all countries in the study are obligated to ensure the progressive realization of the right to health and are obligated to respect, protect, and fulfill that right for all citizens.

Eliminating user fees and reducing out-of-pocket costs

The commitment to provide at least first- and second-line ARVs is consistent with the intention of universal health coverage to ensure that all people can access health care regardless of ability to pay. Eliminating some user fees for people living with HIV (as measured in Chapter 6) proved to be successful and is to be encouraged for other diseases—particularly for the non-communicable diseases that are the leading causes of morbidity in the included countries.

Government-led Policies for Universal Health Coverage and Legislation to Support the Right to Health

The responsibility of ensuring equitable access to health care is ultimately the responsibility of governments and is achieved through policies (Marmot et al. 2008). Given the success of common policy on HIV in these countries, the way forward must include policies explicitly supporting universal health coverage. Despite the efforts of non-governmental

organizations, it is ultimately government policies and initiatives that paved the way for improvements for people living with HIV that are reinforced by the right to health which emphasizes the principle of non-discrimination (Office of the High Commissioner for Human Rights, 2000). Regional legislation supporting non-discrimination in the health sector and in wider society for people living with HIV needs to be enforced. Currently some countries have legislation in place to support the right to health. Policy and legislation should ensure that implementation is consistent with the concept of universal health coverage as outlined by international organizations, such as WHO, PAHO and the World Bank.

Improve Data Capacity and Utilization

Data collection and analysis in the six countries needs to be improved. The lack of country-level data was evident throughout the research, from lack of HIV prevalence rates to household-level data on income and expenditure, as illustrated in Chapter 6. There are currently projects to improve data capacity in the Eastern Caribbean to meet the monitoring requirements for the 2030 SDG indicators, including those for universal health coverage. This is important since universal health coverage emphasizes data disaggregation to get a clearer picture of the reality of access to health care for under-represented groups. The Global Action Plan for Sustainable Development Data is an ongoing effort to improve statistical capacity for the SDGs (United Nations Statistical Division, 2017).

Infrastructural improvements

There is a need for infrastructural improvements in health delivery systems that enhance privacy when obtaining care. Privacy in waiting rooms should be a priority for all people accessing care, not only people living with HIV. Also, improvements in equipment and

infrastructure should be pursued so that testing and delivery facilities are decentralized. There is already attention to improving hospital infrastructure for improved resiliency in the aftermath of disasters through the Smart Hospital Project (Balbus et al., 2016). The responsiveness to the need for appropriate and necessary facilities should be expanded to include renovations that are responsive to privacy concerns.

Privacy standards

The need for privacy in accessing health care was evident in Chapter 5. People living with HIV were not always guaranteed privacy at health facilities—most notably when filling prescriptions and seeing a health care provider—although efforts were made to conceal their identities when submitting blood samples. The right to health both depends on, is related to, and contributes to the right to privacy (Office of the High Commissioner for Human Rights, 2000; Office of the United Nations High Commissioner for Human Rights, World Health Organization, 2008).

The need for privacy is especially important for members of vulnerable groups and people living with HIV. However, everyone utilizing health care should be granted the right to privacy regardless of HIV status, or type of care they are seeking and should be given priority in efforts to achieve universal health coverage. Health service professionals, including administrative and other support staff, should be trained to adhere to standards of privacy. Breaches of privacy need to incur notable penalties since the lack of assurance of privacy can be a deterrent to those seeking care. Since there is not a practice of filing complaints on the right to health, a user-friendly complaints process should be in place that protects individuals filing from further discrimination and retaliation.

Limitations and Recommendations for Future Research

The views of people living with HIV were not included in Chapter 5. This was due to funding constraints that prevented engaging research coordinators in the six countries. Future empirical research must include the voices and perspectives of people on the demand-side of health care. Including health service providers in research cannot be seen as a substitute for the people who utilize health care. Although physicians have made important contributions to the discussion about the right to health, they might have different perspectives than that of patients and their families, and can even sometimes be complicit in human rights abuses (Hunt, 2006; Robinson, 2004). Apart from the issues of agency, and the financial motives of physicians, the question of the competing loyalty of physicians in human rights situations has been acknowledged (Allhoff, 2008; Physicians for Human Rights, 2002). There is room for further studies involving the perspectives of people utilizing health care consistent with the Greater Involvement of People Living with HIV (GIPA) principle which assures that people living with HIV are fully involved at all stages of program delivery and research concerning HIV (UNAIDS, 2007).

Chapter 6 included a test of affordability for only one country—St Lucia. Laws in the other countries prevented the sharing of data, even for research purposes. Future collaborations with governments and local researchers would produce data to assess the needs of individual countries in the Eastern Caribbean. New household surveys are being conducted between 2018 and 2020 in the OECS countries. Future research could review the affordability of medication for diseases that are listed in the 10 leading causes of death in the region.

Follow-up to Chapter 3 would be formulating a detailed evaluation framework for individual countries based on the arguments for participatory and inclusive evaluations for universal health coverage.

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Appendix A: Description of the Health System and Services in the Six Countries in the Study

The following section is a desk study providing an historical overview of the ministries of health, the health system, HIV programs, and delivery arrangements in the six countries.

Antigua and Barbuda

Antigua and Barbuda's National Strategic Plan for health pays particular attention to the importance of the key role that the social determinants of health (which include income, education, social support, physical environment, genetics, and health services) have in maintaining health (Antigua and Barbuda, 2016.). For 2016–2020, the Antigua and Barbuda National Strategic Plan for Health clearly articulated universal health coverage as a goal with the focus being health risk reduction through improved delivery of primary and secondary care, epidemiological surveillance, health planning and health information, pharmaceutical and medical supplies management, health financing, infrastructural development, and expanding strategic partnerships. Revenue for the public health care system mainly comes from the Ministry of Finance and the Medical Benefits Scheme which is a government-funded program that offers financial assistance and pharmaceutical supplies to residents with chronic diseases⁴⁸ (Antigua and Barbuda, n.d; Health in the Americas, 2012).

⁴⁸ These chronic diseases are listed as: asthma, cancer, cardiovascular diseases, certified lunacy, diabetes, epilepsy, glaucoma, hypertension, leprosy, Parkinson's, and sickle cell anemia". See <http://mbs.gov.ag/information/diseases.php>

Antigua and Barbuda's National Business Plan for Health 2008–2010 quotes the 1997 Health Policy document of the Ministry of Health which affirms that the country's public health system is based on the principle of universality as "health is recognized as a basic human right to which all citizens and residents are entitled and which the Government has an obligation to provide" (p. 12).

In 1997, Antigua and Barbuda's National AIDS Programme Policy recognized HIV as a threat to public health and pledged to reduce the impact of the disease (Antigua and Barbuda, 2011). From 2005–2010, heart disease, malignant neoplasms, diabetes mellitus, hypertensive disease, and accidental and intentional injuries were the leading causes of mortality (PAHO, 2012a). Non-communicable diseases were the leading cause of death from 2000–2013 (see Figure A-1), while the number of people living with HIV mostly increased for roughly that same period (see Figure A-2)

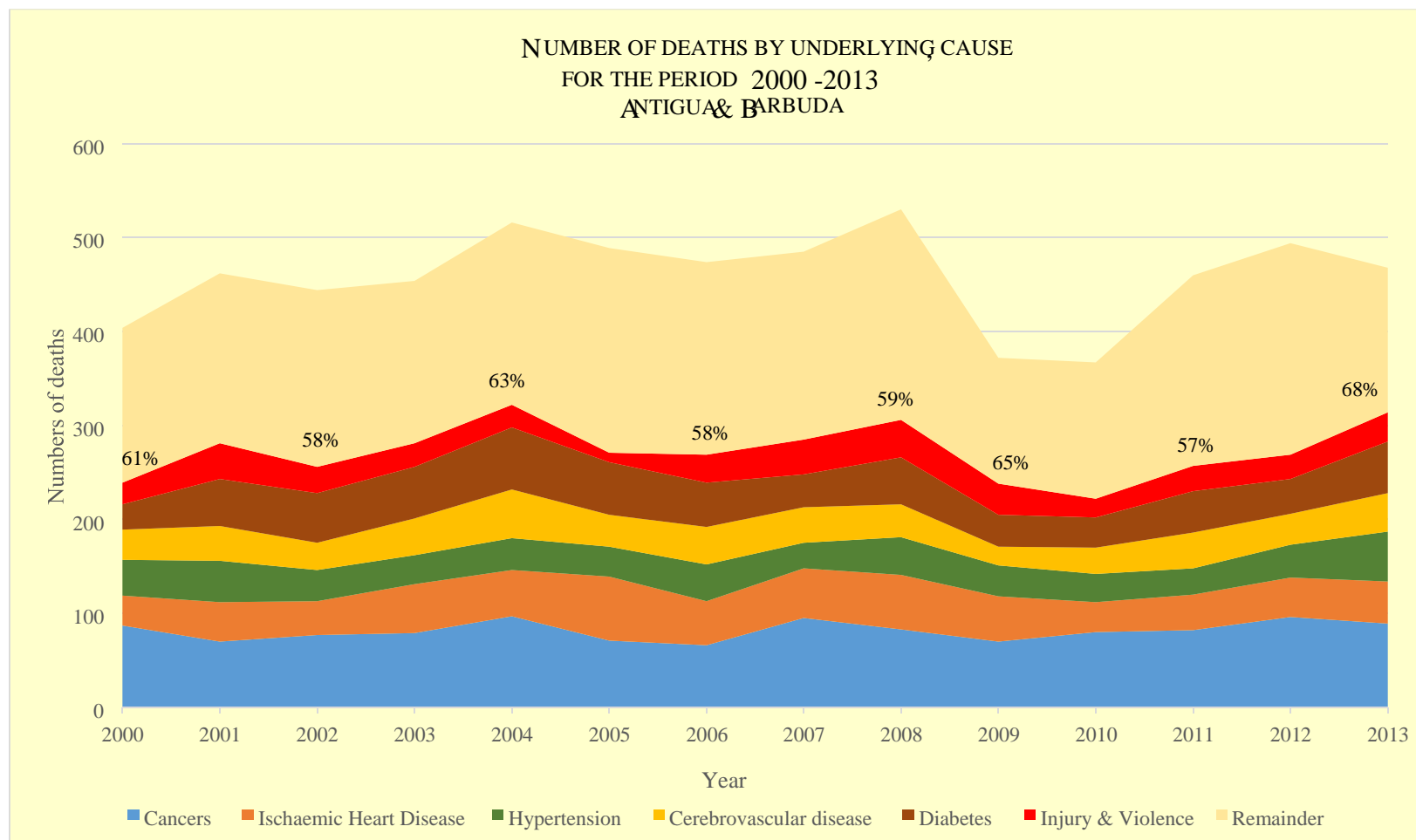


Figure A-1. Number of deaths by underlying cause in Antigua & Barbuda: 2000 to 2013

Note: Non-communicable diseases are responsible for half to one-third of all deaths in Antigua and Barbuda for this period.

Source: CARPHA (Obtained from <http://carpha.org/Portals/0/DataAndStatsWebPage/Mortality/Antigua%20and%20Barbuda%20mortality.pdf>)

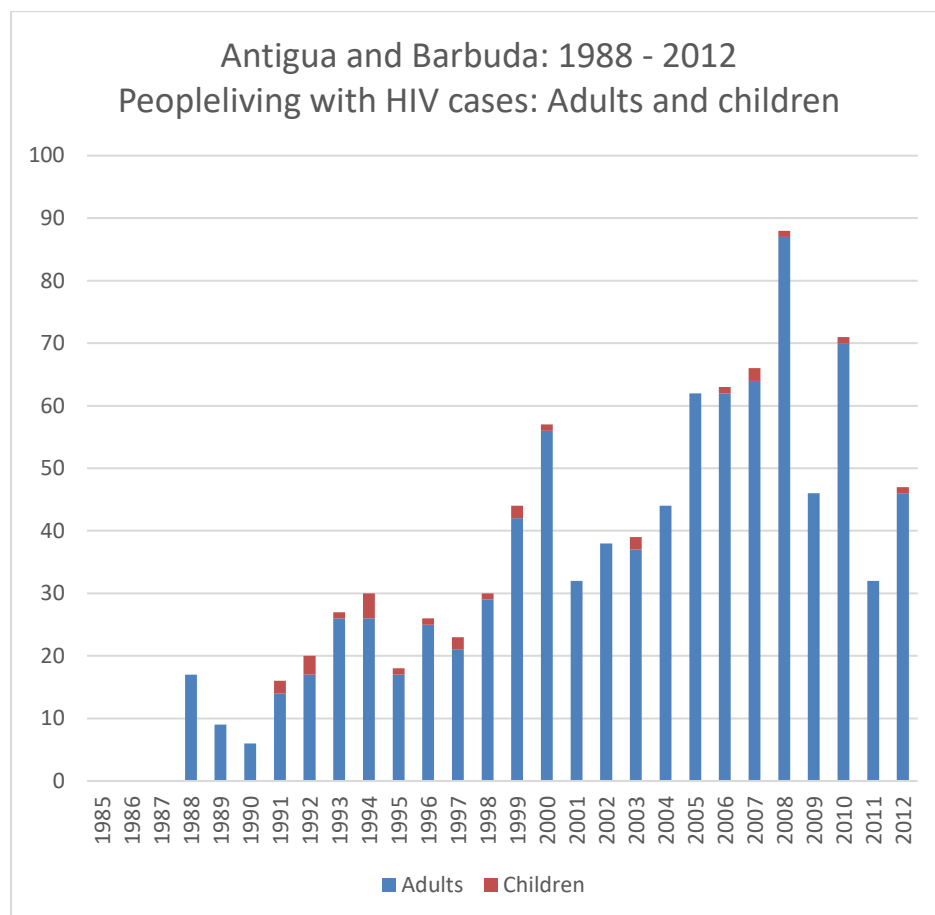


Figure A-2. HIV cases (adults and children) in Antigua and Barbuda from 1988 to 2012

Dominica

Dominica’s 2010–2019 National Strategic Plan for Health provides an overview of the main health challenges which include non-communicable diseases (cardiovascular disease, diabetes, and rising incidence of cancer) (Commonwealth of Dominica, 2010a). There is strong emphasis on raising public awareness as a strategic response to these diseases. The national strategic health plan also notes that unaffordable, nutritious food has resulted in food security being a problem (although the scope of the problem was not fully identified). As of 2018, the

most recent country poverty assessment conducted from 2008 to 2009⁴⁹ recorded 28.8% of adults living below the national poverty line which means this proportion of the adult population could not maintain the minimum consumption of food and non-food requirements (Kairi Consultants, n.d.). The demise of the banana industry in the 1990s—a main source of income for many households—resulted in mass migration as income earners sought employment overseas which weakened local social support systems (Commonwealth of Dominica, n.d.).

The leading causes of death for 2006–2010 were cerebrovascular disease, diabetes mellitus, ischemic heart disease, hypertensive disease, and malignant neoplasm of the prostate. HIV was not among the 10 leading causes of death in Dominica for this time period (PAHO, 2012b). For 2000–2013, various types of cancers were the cause of a substantial proportion of mortality in Dominica with an increase in mortality due to cerebrovascular disease and a decrease in deaths due to hypertension (see Figure A-3).

In 2010, the Ministry of Health identified HIV as a communicable disease with epidemic potential and made sustained response to the disease a priority with the intention of reducing HIV incidence by 50% by 2018 (Commonwealth of Dominica, 2010a; Commonwealth of Dominica, 2010b). From 1997 to 2013, males in their 30s comprised the majority of people living with HIV (see Figure A-4).

The National HIV/AIDS Response Unit (NHRP) in the Ministry of Health coordinates the HIV response and consults with civil society organizations, faith-based organizations, youth

⁴⁹ Dominica's 2010 Strategic Plan for Health does not cite the 2008 estimate of 28.8% of the adult population living below the poverty line, but refers to the 2002 estimate of household poverty of 29%.

organizations, private sector and trade unions (Government of the Commonwealth of Dominica, 2008). Stigma and discrimination were challenges that the national HIV program faced, along with policy development and legislative reform, and the appropriate level of financial resources (Government of Commonwealth of Dominica, n.d.).

Dominica reported 100% success in the prevention of mother-to child transmission (PMTCT) since the inception of the PMTCT program in 2001 (Government of the Commonwealth of Dominica, 2012). AIDS-related deaths decreased from 12.8% in 2002 to 5.6% in 2007 (Government of Commonwealth of Dominica, n.d).

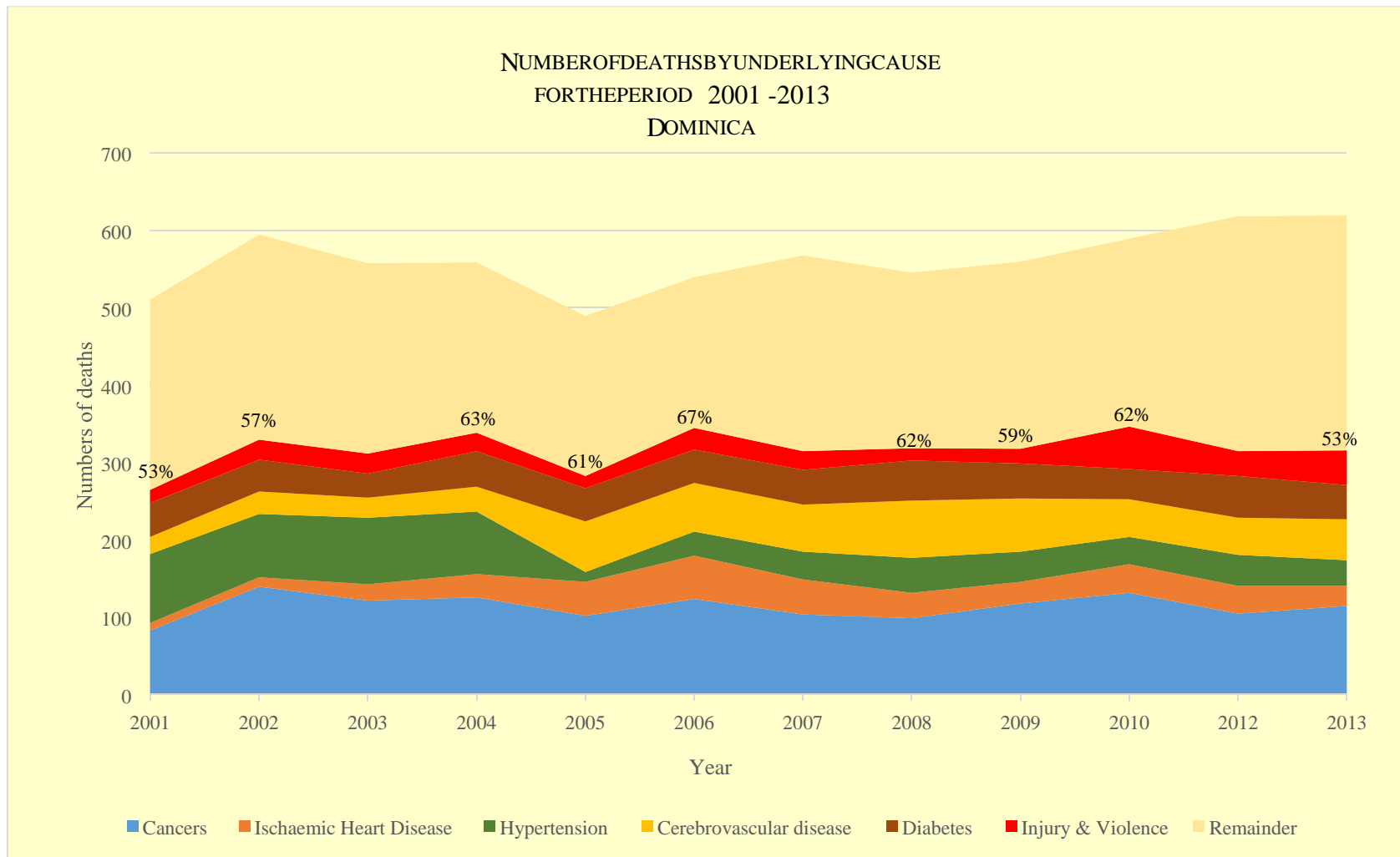


Figure A-3. Number of deaths by underlying cause in Dominica for the period 2000 to 2013
 Source: CARPHA (Obtained from <http://carpha.org/Portals/0/DataAndStatsWebPage/Mortality/Dominica%20mortality.pdf>)

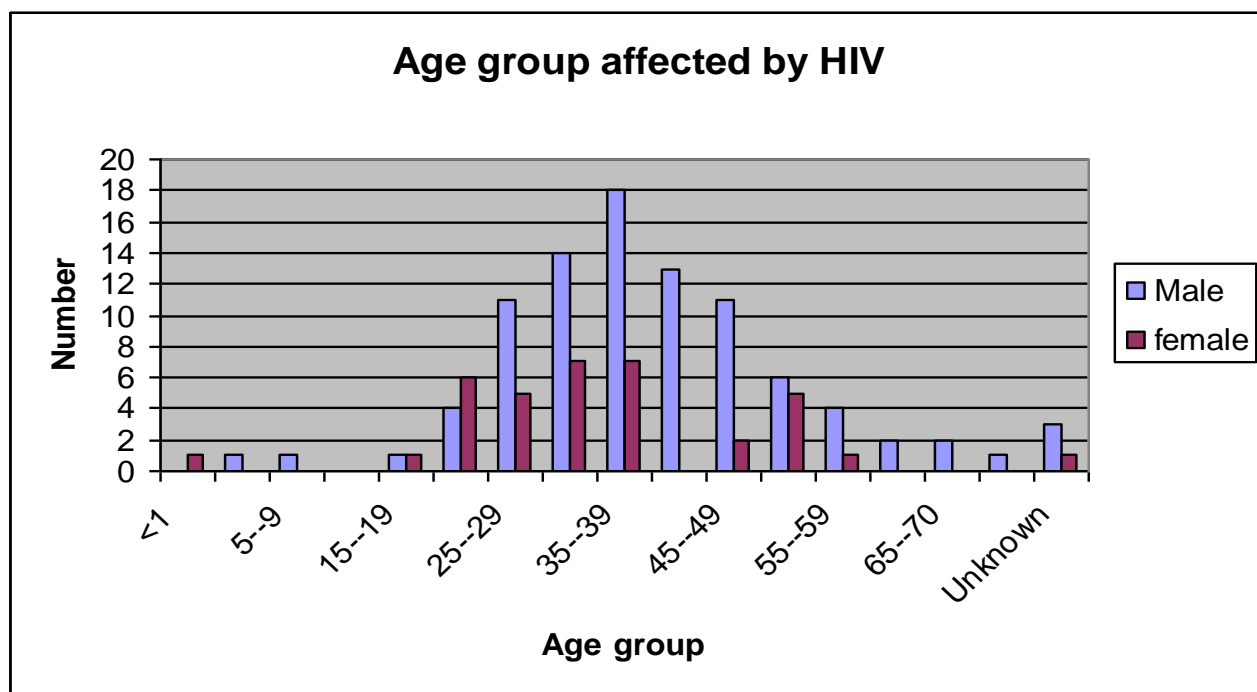


Figure A-4. Number of HIV cases by age group in Dominica from 1987 to 2013

Source: National AIDS Program Coordinator, Dominica

Grenada

Grenada’s 2016 to 2025 Strategic Plan for health presents a view of a health system that could benefit from legislation and policies that would support the Ministry of Health in achieving its goals (Government of Grenada, n.d). The strategic plan provides a candid assessment of the need for legislative and policy changes concerning adolescent health, the changing needs of the aging population, waste management, and local pharmaceutical management. The major challenges for providing HIV care in the 2016 to 2025 plan were noted as the “[f]ailure of diagnosed persons to disclose their status to their sexual partner(s), [o]ccasional stock outs of reagents, [a]bsence of Rapid Testing, [l]ack of adherence to medication by some patients, [a]bsence of budgetary allocation to manage the HIV/AIDS programme in the absence of donor

fund[s], [w]eak data collection mechanisms to strategically guide focus, [a] [c]entralized clinic for treatment and care of HIV-positive persons [that] result[s] in economic burden [being placed] on patients as well as staff” (Government of Grenada, n.d, p. 25).

The National AIDS Council of Grenada is a multi-sectoral body responsible for the Grenada National AIDS Program through oversight, advisory, and policy-making (Grenada 2010 Country Report). The draft National Strategic Plan for HIV/AIDS developed for 2008 to 2012 and focused on behaviour change interventions; stigma & discrimination reduction using a human-rights-based approach to providing treatment and care; and scaling up of access to treatment, care, and support especially in underserved and vulnerable communities. Risky sexual behaviour among young people, including early sexual initiation, belief in myths about HIV, and stigma about the disease, were areas identified for action in the Grenada National HIV/AIDS Strategic Plan 2012-2016 (Grenada Ministry of Health, 2012). From 2000 to 2012 non-communicable diseases remained the leading cause of death with an unexplained decline in deaths in 2008.

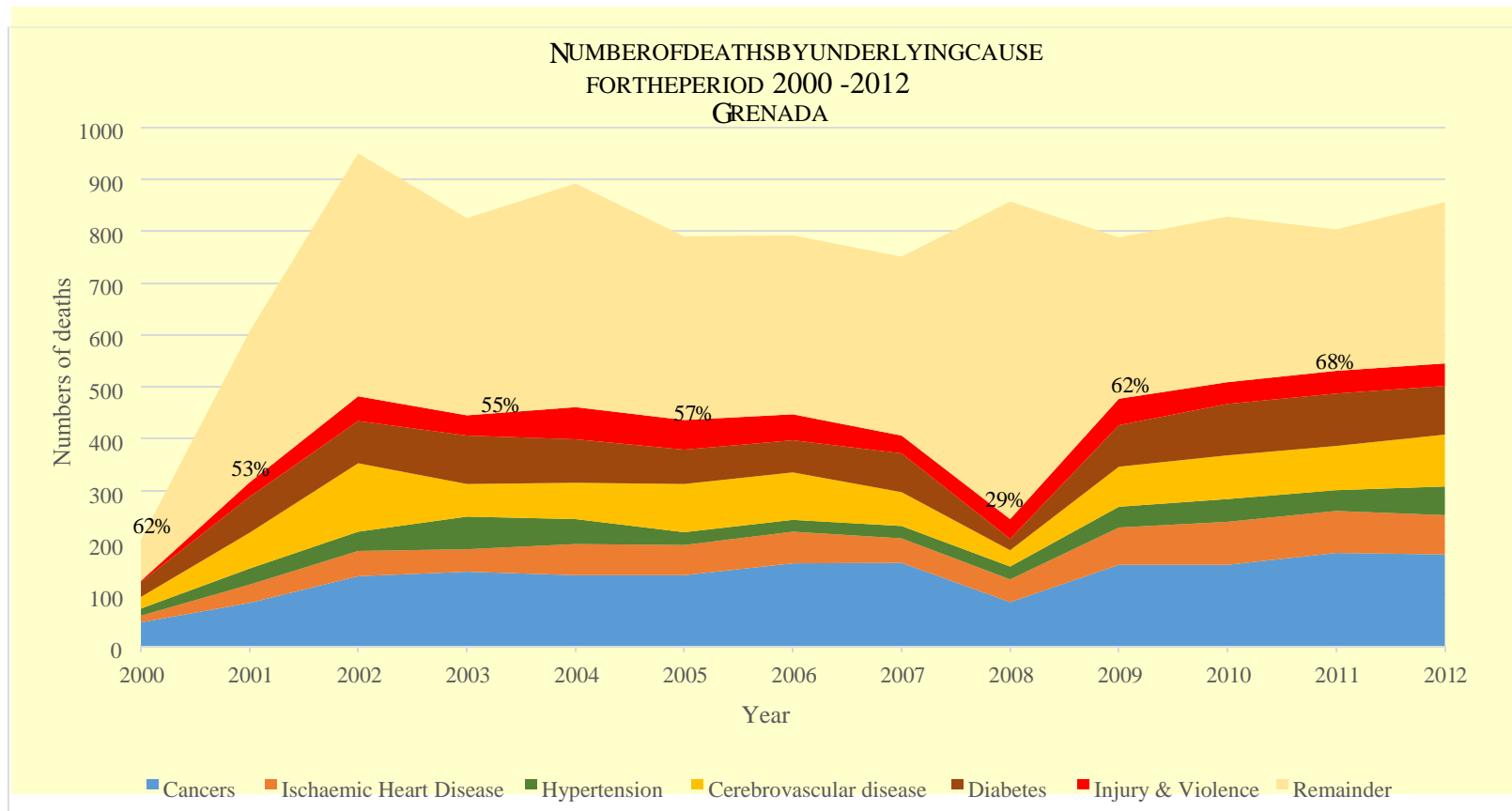


Figure A-5. Number of deaths by underlying cause in Grenada for the period 2000 to 2012
Source: CARPHA (Obtained from <http://carpha.org/Portals/0/DataAndStatsWebPage/Mortality/Grenada%20mortality.pdf>)

Grenada's National Program of the Prevention of Mother-to-Child Transmission was started in 2003 and promotes HIV testing for all pregnant women attending public health antenatal clinics, infant formula and antiretroviral therapy for all HIV-positive mothers in Grenada (Grenada Ministry of Health, 2008).

The National Infectious Disease Control Unit in Grenada's Ministry of Health oversees the provision of treatment, care, and support to people living with HIV in collaboration with other departments in the Ministry of Health departments such as pharmacy, Pathology Laboratory, and community health facilities (Grenada, 2010). The Unit provides a wide range of clinical care, psychosocial counselling, ancillary support to clients and their relatives, condom education and distribution, as well as pre- and post-test counselling, and services to prevent mother-to-child transmission (Grenada, 2010). For the 1986 to 2012 period, the number of people living with HIV in Grenada peaked in 2007, with notable increases in the number of people aged 55 and over living with the disease (see Figure A-6).

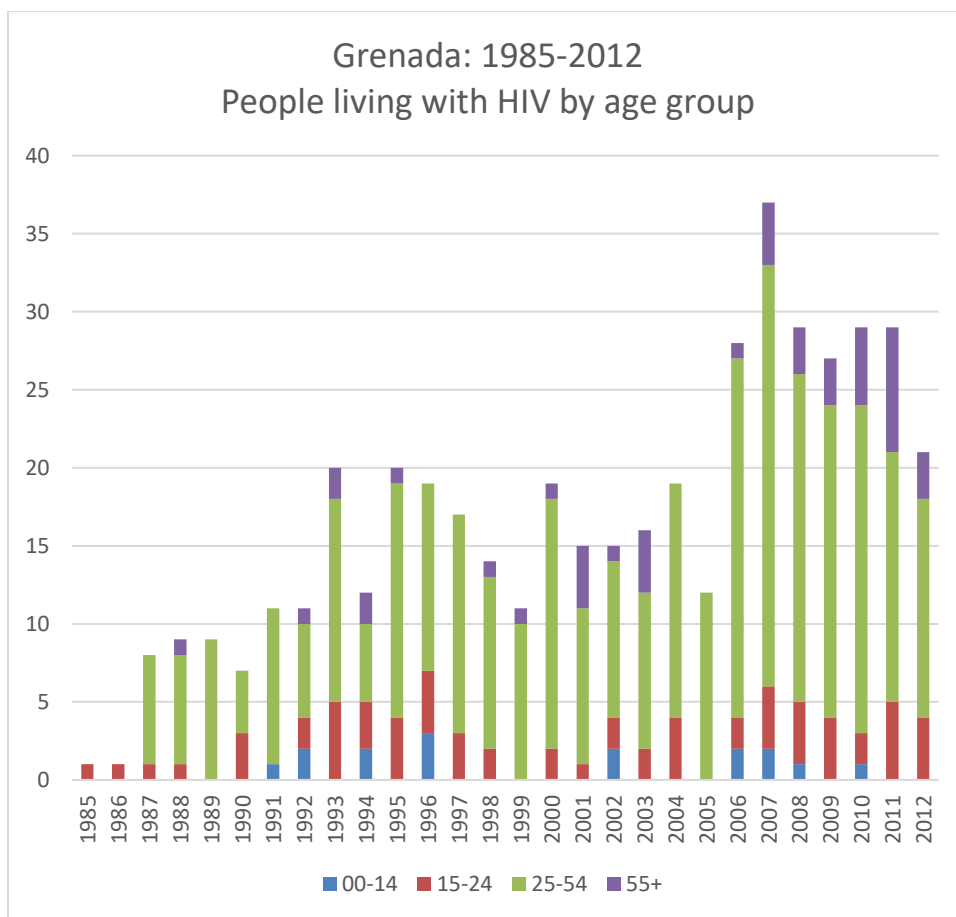


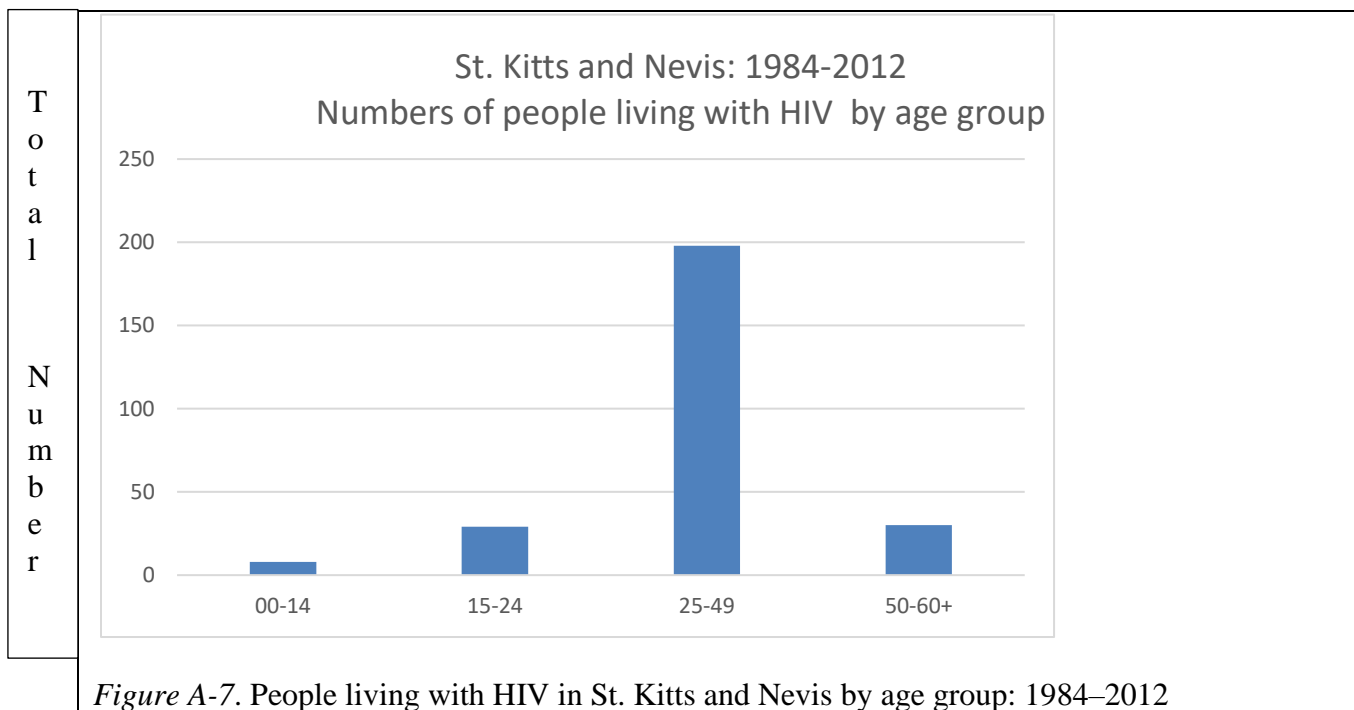
Figure A-6. People living with HIV in Grenada by age group: 1985 to 2012

St. Kitts and Nevis

In February 2018, St. Kitts and Nevis launched a Commission to advance implementation of a national health insurance initiative to advance universal health coverage. This would update the existing policy where user fees are charged for adults who use public facilities and purchase pharmaceuticals (USAID, 2012b).

For children receiving primary- and secondary-level care and seniors over the age of 62, health care services and medications are free. The public sector system is perceived by many to be targeted to these two populations, although there are no formal restrictions.

Voluntary HIV counselling and testing services, although widely available, are under-utilized because of perceptions of low confidentiality and the possibility that past sexual partners would be notified through a “contact tracing/partner notification” protocol (Giasecke et al. 1991; Rutherford, 1988; St. Kitts and Nevis, 2008). A program for preventing mother-to-child transmission (PMTCT) has been in place since 2005 and has effectively kept mother-to-child transmission of HIV low from 1984 to 2012 (see Figure A-7). The need to increase the involvement of men in PMTCT in St. Kitts and Nevis has led to a renaming of the service to Prevention of Partner to Mother to Child Transmission Services (St. Kitts and Nevis, 2010).



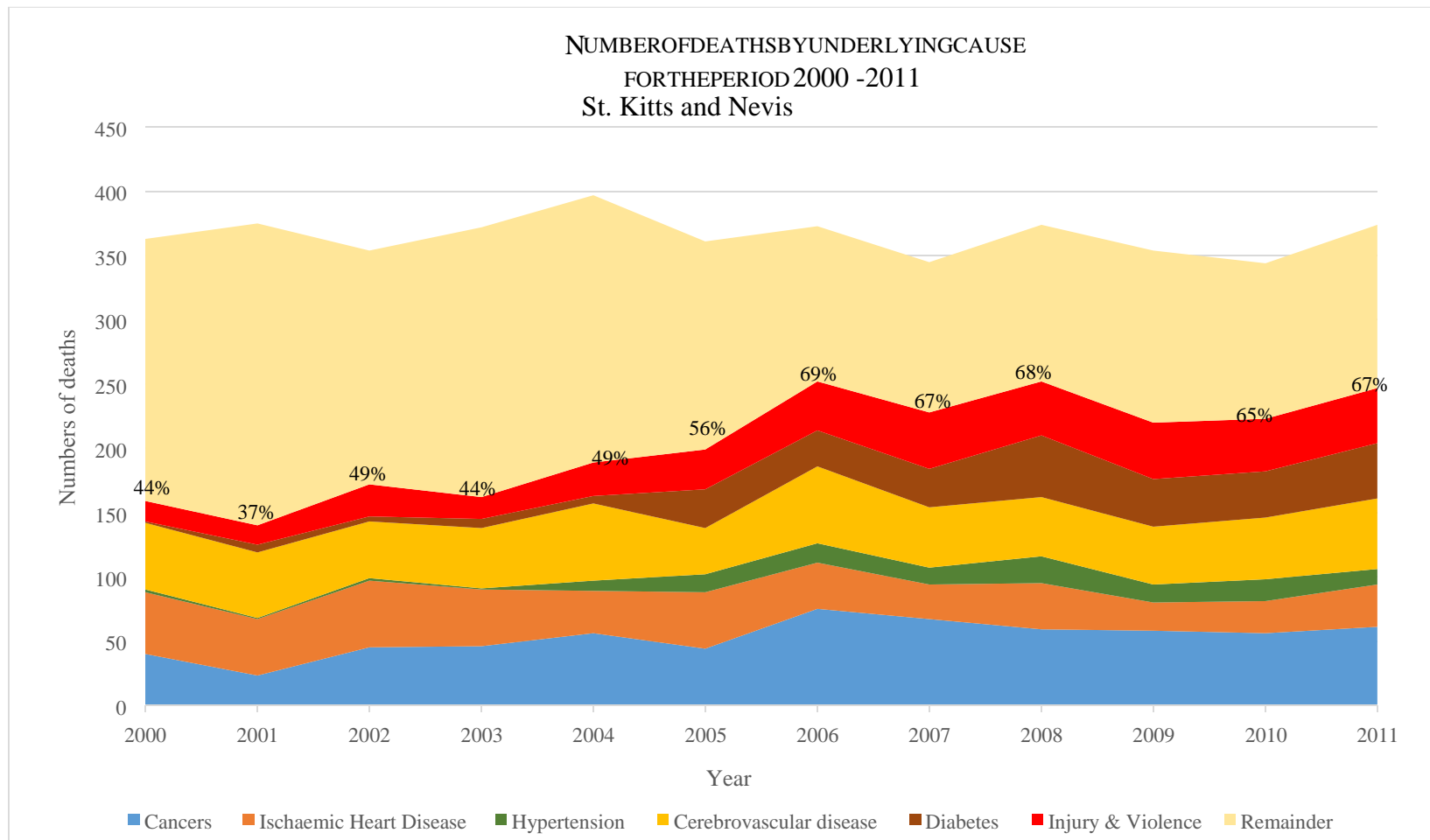


Figure A-8. Number of deaths by underlying cause in St. Kitts and Nevis from 2000 to 2011.
 Source: CARPHA (Obtained from http://carpha.org/Portals/0/DataAndStatsWebPage/Mortality/St%20Kitts_Nevis%20mortality.pdf?timestamp=1534357468882)

For the 2000 to 2011 period, HIV was not among the leading causes of death. There has been a notable increase in the impact of non-communicable diseases for that period, with most mortality being attributed to cancers, diabetes and injuries (see Figure A-8).

St. Lucia

The St. Lucia National Coordinating Committee on HIV/AIDS was formed in 2003 to advise and support the AIDS Secretariat in the Ministry of Health. In 2003, the HIV prevalence rate was estimated at 0.12%. The 25–49 age group was most vulnerable to the disease from 1985–2012 (see Figure A-9). Specifically, in 2003, the 25–34 age group accounted for 32.5% of infections (St. Lucia, 2003). There are four main strategies for responding to HIV aligned with PANCAP’s Regional HIV/AIDS Strategic Framework. The areas are: (a) advocacy, policy development through political commitment, and protecting the rights of people living with HIV; comprehensive care for all persons living with HIV/AIDS (b) preventing further transmission of HIV through scaled up HIV care and support; guidelines and protocols and interventions in the workplace; community and health care system; (c) preventing further transmission of HIV through voluntary counselling and testing, PMTCT and activities for vulnerable groups and young people in and out of school; (d) strengthening national capacity to deliver an effective coordinated and multi-sectoral response to the epidemic through research, surveillance, institutional strengthening and management of the National Coordinating Committee on HIV/AIDS. PMTCT has been successful in St. Lucia. Due to scale-up of testing of pregnant women, there has not been a single case of peri-natal transmission of HIV in St. Lucia among all those enrolled in care since 2006 (St. Lucia, 2012).

At the two public laboratories in St. Lucia, a fee is charged for many tests done at the primary level, including tests for cholesterol and diabetes, and this serves as a disincentive to obtain the tests. The very poor are fee-exempt from such tests, but not all pensioners are exempt (USAID, 2012c). Although CD4 tests (that track the body’s antibody-fighting capacity in the presence of HIV) were conducted at no cost to patients, it had been reported that only 23% of people returned for their test results (Jules et al., 2009). As with other OECS countries, non-communicable diseases make up a large proportion of deaths, with cancer deaths being particularly high (see Figure A-9).

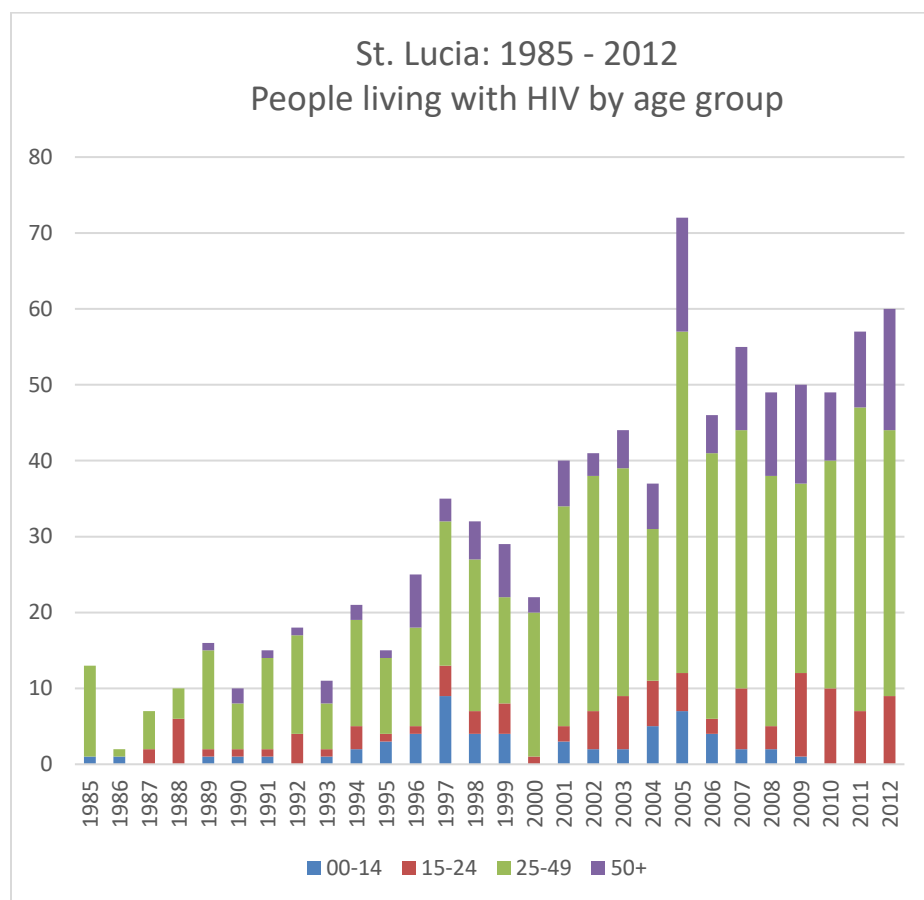


Figure A-9. People living with HIV by age group in St. Lucia from 1985 to 2012

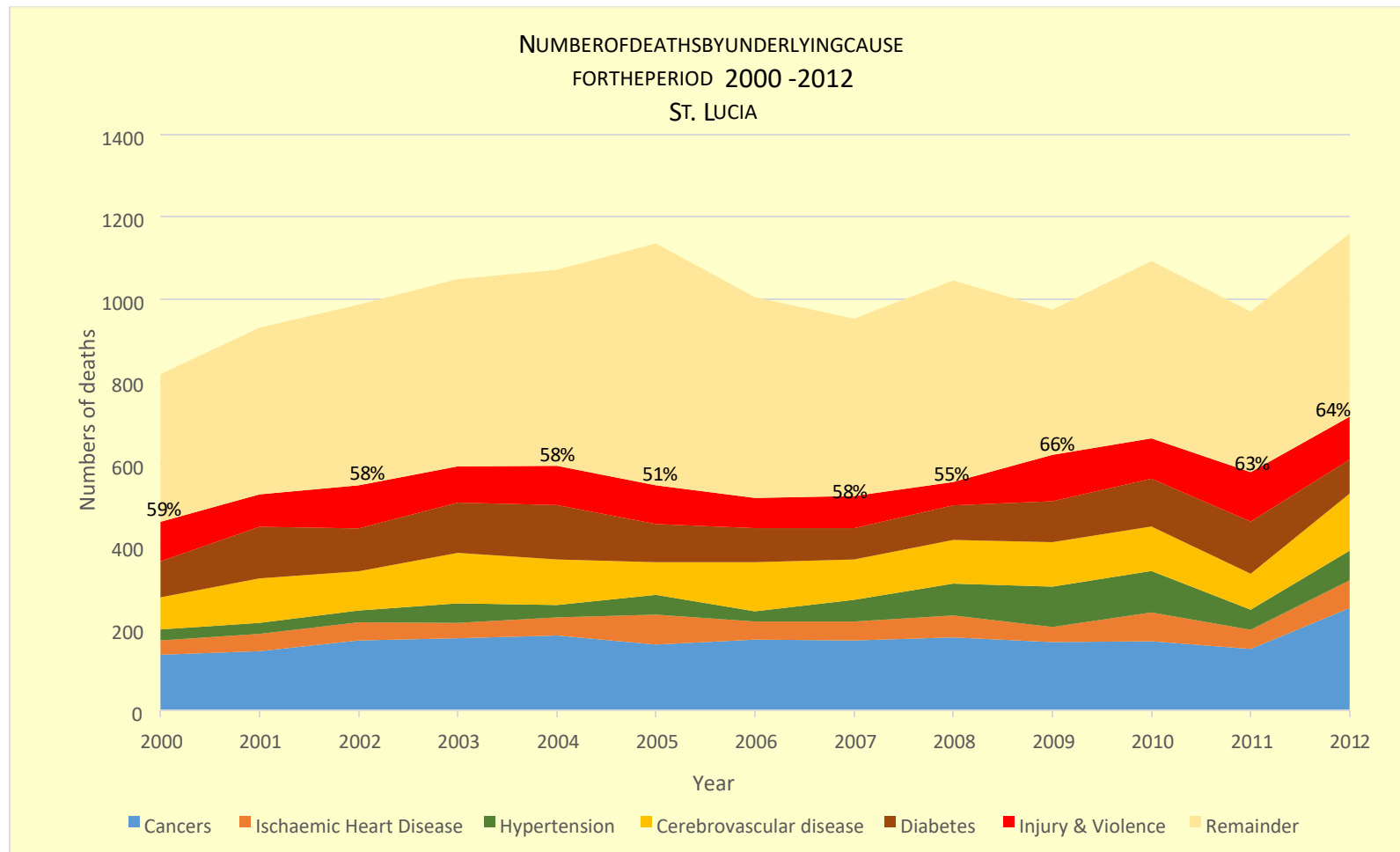


Figure A-10. Number of deaths by underlying cause in St. Lucia from 2000 to 2011
 Source: CARPHA (Obtained from <http://carpha.org/Portals/0/DataAndStatsWebPage/Mortality/Saint%20Lucia%20mortality.pdf>)

3,000. Geographic accessibility is good, with no one having to travel more than three **St.**

Vincent and the Grenadines

Primary health care is offered through 39 health centres in the country's nine health districts, seven on the island of Saint Vincent and two in the Grenadines. Each health centre is equipped to cover an average population of approximately miles to receive care. Secondary care was mainly provided at the 211-bed Milton Cato Memorial Hospital, the country's only government-run, secondary-care referral institution (Health in the Americas 2012). Decisions on budgets, human resources, are made by the Ministry of Health. There is no tertiary care available locally (USAID, 2012d).

The HIV/AIDS Unit in the St. Vincent and the Grenadines Ministry of Health Wellness and Environment manages the HIV program. A Monitoring and Evaluation Reference Group within the National AIDS Secretariat provides technical support and advice with the implementation of the HIV/AIDS Monitoring and Evaluation (M &E) Plan and is supported by international, regional, and bilateral partners in capacity building, development and installation of a patient-tracking system, development of indicators, development of monitoring and evaluation plan, financing assessment of the laws of St. Vincent and the Grenadines, and training in patient monitoring (St. Vincent and the Grenadines, 2009).

Prevention of mother to child transmission of HIV services are offered at no cost to all HIV-positive pregnant women which has resulted in the elimination of mother to child transmission of HIV (St. Vincent and the Grenadines, 2009). From 2000 to 2012, heart disease, cancer and other non-communicable diseases were the leading causes of death (see Figure 4-14).

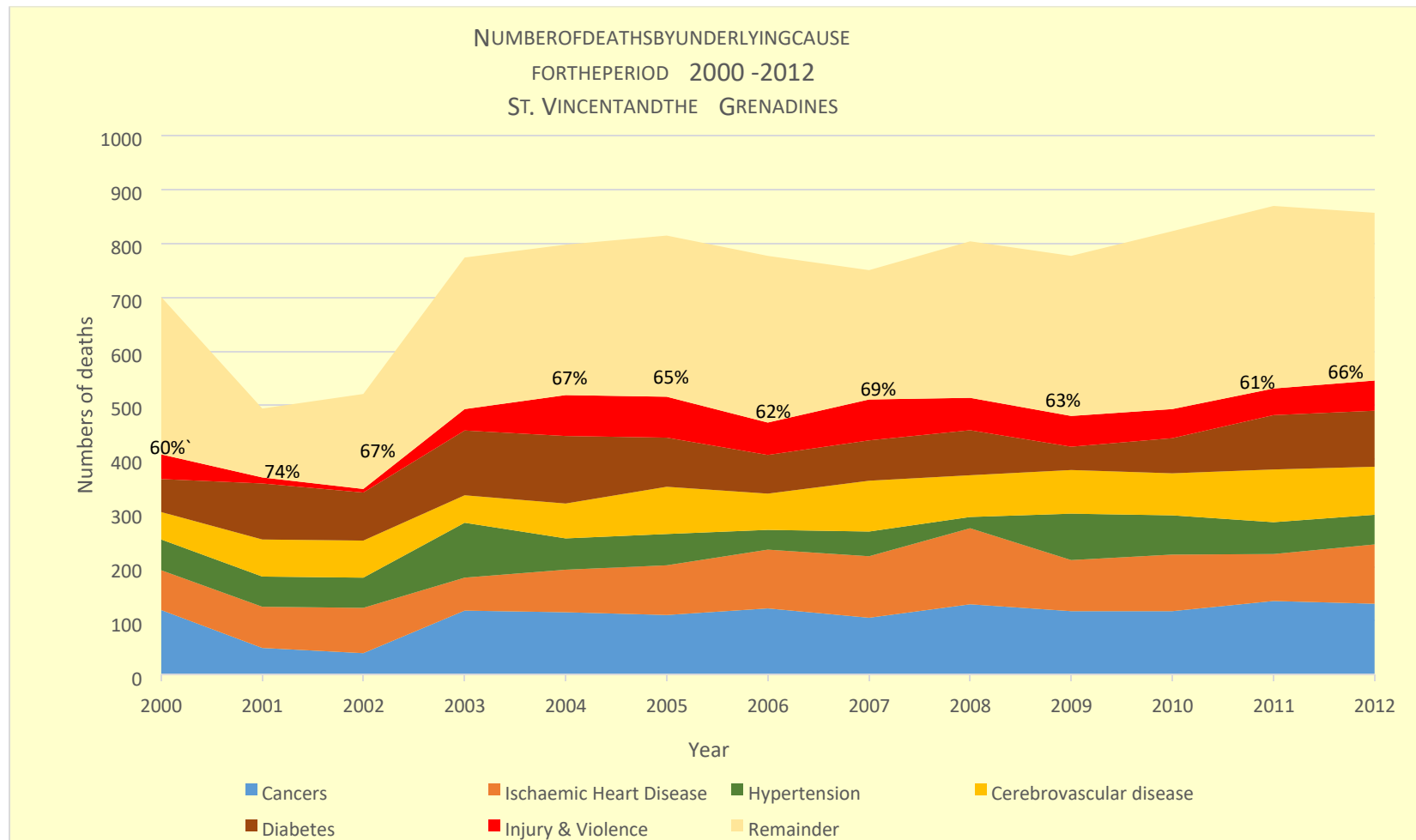


Figure A-11. Number of deaths by underlying cause in St. Vincent and the Grenadines for the period 2000 to 2011
 Source: CARPHA (Obtained from <http://carpha.org/Portals/0/DataAndStatsWebPage/Mortality/SVG%20mortality.pdf>)

Appendix B: Economic and Development Profile of OECS

Antigua/Barbuda and St. Kitts Nevis are high income countries and the other four countries included in this dissertation (Antigua and Barbuda, Dominica, Grenada, St. Lucia and St. Vincent and the Grenadines) are upper-middle-income countries. However, using the World Bank's income classification cut-offs to define the OECS economies as upper-middle-income or high-income obscures the economic reality of these countries. The income cut-offs for the respective income groups are based on the World Bank's operational guidelines for lending (World Bank, n.d.-c). From 2003 to 2012 Antigua/Barbuda has vacillated between the upper-middle and high-income category and St. Kitts and Nevis had been consistently upper-middle income until it advanced to the high-income bracket in 2012.⁵⁰ The other three countries—Dominica, Grenada, and St. Vincent and the Grenadines—were classified as upper-middle-income countries for that period.

GDP and GNP do not adequately convey the economic vulnerability of small island developing states (Briguglio, 1995). Natural disasters subject countries to macroeconomic shocks that are evident in economies that are not particularly resilient. The six Eastern Caribbean countries are among the “most disaster-prone in the world” and from 1970 to 2004 have been among the 10 countries most subjected to natural disasters (Rasmussen,

⁵⁰ For history of classification from 2003-2013, see
<http://siteresources.worldbank.org/DATASTATISTICS/Resources/OGHIST.xls>

For Antigua 2003-2004 (UM); 2005-2007 (H) 2009-2011 (UM) and 2012 (H). For that same period until 2010

2004, p. 7). The OECS countries are surrounded by the Caribbean Sea and are intrinsically vulnerable to hurricanes and floods because of large coastal zones and small exposed interiors, and geographic proximity to the equator which places them in the “Atlantic hurricane belt” (Pelling et al. 2001). Small economies are impacted by natural disasters when the agricultural sector is impacted, villages are decimated, individuals die or are injured, the communications sector is disrupted, and those which are tourism-based experience decline in arrivals due to infrastructural damage (Briguglio, 1995; Crowards, 2000). Macroeconomic implications of natural disasters on small economies are an immediate contraction in economic output, worsening external balances due to increased imports for reconstruction materials, deteriorating fiscal balances due to shrinking tax revenues, and an increase in poverty since natural disasters disproportionately impact the poorer segments of the population (Rasmussen, 2004). Crowards (2000) establishes the vulnerability of Eastern Caribbean countries on the following measures: number of historical episodes over approximately 100 years; changes in macroeconomic variables before and after specified events; volatility of agricultural production over 20 years; damage costs (of a limited number of disaster events); number of persons affected (by identified events over the past 30 to 50 years); and number of deaths attributed to natural disasters over the past 30 to 50 years.

Despite these environmental vulnerabilities, the OECS have maintained high levels of development denoted by the UNDP’s HDI which determines their relative human development ranking. Table B-1 compiles data of frequently-used economic and development indicators for the OECS.

Table B-1

Summary of Economic and Development Indicators for the Six OECS Countries

GNI per capita US\$ ATLAS Method (2012)¹	12480		Antigua Barbuda	Dominica	Grenada	St. Kitts/ Nevis	St. Lucia	St Vincent & Grenadines
Ratio of total external debt to GNI (2012) ³	*N/A	GDP per Capita in US\$ PPP (2012) ¹	19640.35	12426.1	10927.94	18383.76	11427.2	11046.67
% Unemployment Rate (Year) ⁴ (2011)	10.2%	Debt-to-GDP Ratio (2011) ²	93.4%	71.2%	103.7%	154.3%	70.1%	68.1%
HDI Rank out of 186 countries (2012) ⁵	67	72	63	72	88	83		
HDI Value (2012) ⁵	0.760	0.745	0.770	0.745	0.725	0.733		
Gini Index of Inequality ⁶ (Year)	0.49 (2005/2006)	0.44 (2007/2008)	0.397 (2008)	0.367 (2007/2008)	0.42 (2005/2006)	0.402 (2005/2006)		

*N/A Antigua/Barbuda does not borrow from the World Bank it is not required to report to the World Bank Debtor Reporting System Data sources:

¹World Bank <http://databank.worldbank.org/data/home.aspx>

²International Monetary Fund <http://www.imf.org/external/pubs/cat/longres.cfm?sk=24332.0>

³World Bank (2012) Global Development Finance: External Debt of Developing Countries. Retrieved from http://data.worldbank.org/sites/default/files/gdf_2012.pdf

⁴Provided to author by Statistics Departments of respective countries

⁵UNDP <https://data.undp.org/>

⁶Caribbean Development Bank <https://www.caribank.org/publications-and-resources/poverty-assessment-reports-2>

Using the HDI as a gauge, the OECS have maintained relatively high levels of development.

The HDI is a composite index incorporating three basic variables: life expectancy, literacy and GDP per capita (UNDP, 1990). If the argument that national income is inadequate to denote development status⁵¹ has been used to dispute the validity of the World Bank's

⁵¹ "In general discussions in Bank reports, the term 'developing economies' has been used to denote the set of low and middle income economies" (http://data.worldbank.org/about/country-classifications?print&book_recurse).

income classification system, the same holds true for UNDP's HDI since it uses GDP as one of its indicators. The HDI has been the target of criticism for relying on indicators that are not necessarily representative of development, the unavailability of life expectancy data in more than half of the less developed countries, the lack of standardization of methodologies to calculate literacy rates and national income, and its reliance on three inter-related indicators (Dasgupta & Weale, 1992; Srinivasan, 1994; McGillivray 1991). However, Bagolin and Comim (2008) consider that the HDI has endured despite these observations and has not made methodological adaptations in response to these critics.

Briguglio (1995) includes population size and national income as characteristics that indicate SIDS' small size. In the world ranking of country size, OECS countries are ranked in the range 170–185 out of a list of 192 countries where 192nd country is the smallest (World Atlas, n.d.). Small population sizes create limitations in public administration for specialist professions (Briguglio, 1995). Table B-2 shows the population and land area of OECS countries.

Table B-2

Population and Land Area of the Six OECS Countries

	Antigua Barbuda	Dominica	Grenada	St. Kitts/ Nevis	St. Lucia	St Vincent & Grenadines
Population (2012) ¹	81799	71293	105143	46204	166526	109,188
Land area Sqkm (sq miles) ²	443.00 (171.04)	754.00 (291.12)	344.00 (132.82)	261.00 (100.77)	616.00 (269.97)	389.00 (150.19)

Constraints in monitoring and evaluation capacity for HIV cited by the OECS might be attributed to staffing limitations (Grenada, 2008; Sulzbach et al., 2012; Government of Antigua and Barbuda, 2007; St. Lucia, 2012, St. Kitts and Nevis, 2012; Dominica, 2012). More than being an indicator of size, GDP has been used as a proxy for welfare of a country's citizens and evidence of a country's level of economic development (van den Bergh, 2009). If GDP per capita for the OECS countries is relatively high, it is not representative of individuals in the lower income brackets and does not capture the disparity in the economy (Ravallian, 2001). The Gini Index addresses this criticism by measuring inequities in income or consumption (World Bank, n.d.-d). Since 0 represents total equality and when expressed as a decimal 1 is perfect inequality, the inequity in the OECS economies is evident ranging from 0.367 to 0.49. High levels of unemployment in the countries ranging from 13.9% to 24.9% provide further insight into the economic challenges the countries face.

The level of debt is another factor in the consideration of economic health. By different measures, the OECS countries are experiencing stifling external debt. The debt-to-GDP ratio is another indicator of economic health which compares a country's sovereign debt to its total economic output for a given year (Abbas, Belhocine, El Ganainy, & Horton, 2010a). While some public debt is expected and responsible debt management is a feature of modern economies, Caner & Koehler-Geib (2011) estimate that debt-to-GDP thresholds above 77% justify concern. Using estimates from the International Monetary Fund compiled from its World Economic Outlook database from 2002 to 2011, all of the OECS countries (with the exception of St. Lucia and St. Vincent) have maintained debt-to-GDP ratios above 77% (Abbas, 2010b). Judging from member countries' reports to the World Bank's Debtor Reporting System on the status of loans from the International Bank for Reconstruction and Development loans or credits from International Development Association, most OECS countries are carrying a significant amount of external debt (World Bank, 2012).

Appendix C: International HIV Assistance by Donor Governments 2002 to 2015

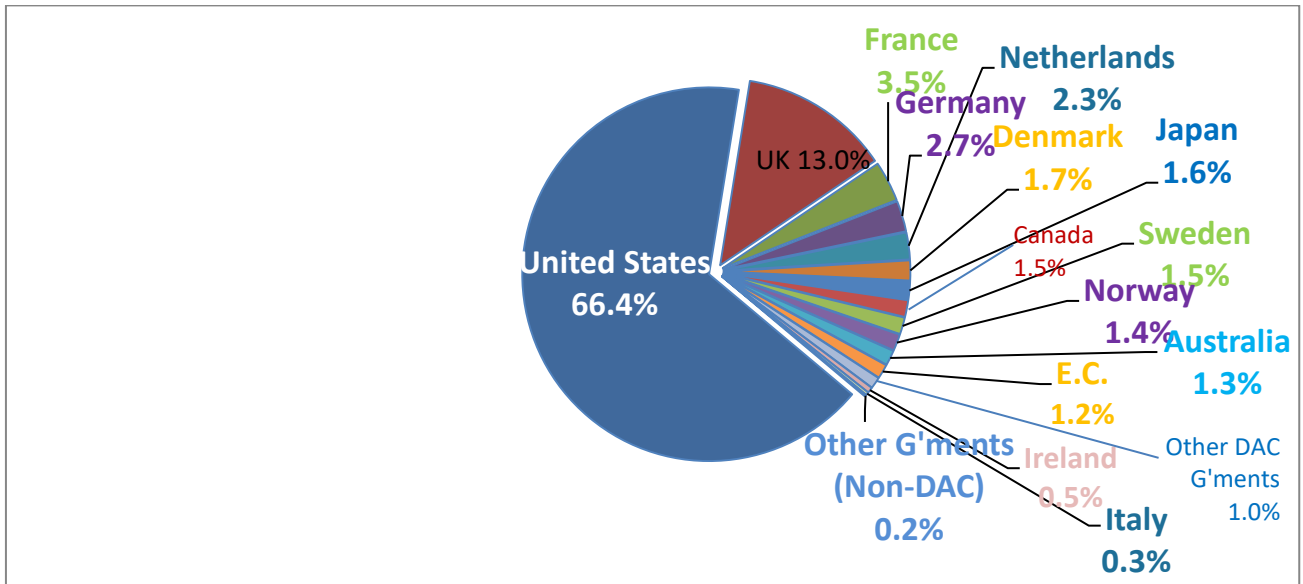


Figure C-1. International HIV assistance: Donor governments as a share of total donor government disbursements, 2002–2015
(Compiled by Kaiser Family Foundation) SOURCES: UNAIDS and Kaiser Family Foundation analyses; Global Fund to Fight AIDS, Tuberculosis and Malaria online data queries; UNTAID Annual Reports; OECD CRS online data queries.

Appendix D: Global Morbidity and Mortality for MDG Diseases in 2000

Table D-1

Global Morbidity and Mortality of Malaria, Tuberculosis, and HIV for 2000

	Malaria		Tuberculosis		HIV	
Year	Deaths	Confirmed Cases	Deaths (Non-HIV)	Prevalence (Non-HIV)	HIV-related deaths	Estimated PLHA
2000	88,042	50,538,977	1,361,811	16,025,721	1,900,000	28,700,000

Notes. Sources of information:

Malaria: (World Health Organization, 2014a)

Tuberculosis: (World Health Organization, 2014b). Reports from years 2002 and 2014

HIV: UNAIDS, 2015

<http://www.unaids.org/en/resources/campaigns/globalreport2013/globalreport>

PLHA – People Living with HIV/AIDS

Appendix E: Significant Global Initiatives for MDG Diseases up to 2001

Table E-1

Timeline of Significant Global Initiatives for Malaria, Tuberculosis, and HIV up to 2001

HIV	Malaria	Tuberculosis
<p>1987: WHO establishes the Global Program on AIDS which was replaced by UNAIDS in 1996⁵²</p> <p>2000: United Nations Security Council resolution 1308 (stressed that “all relevant United Nations organizations to address the HIV pandemic in line with their respective mandates and to assist, wherever possible, in global efforts against the pandemic” and expressed concern “at the potential damaging impact of HIV/AIDS on the health of international peacekeeping personnel, including support personnel” (United</p>	<p>1955: Eighth World Health Assembly votes to start a global malaria eradication program⁵⁵</p> <p>1973: Global Malaria Eradication campaign was discontinued after WHA found time-limited eradication programs to be unfeasible. Some limited financial assistance was promised to countries that made requests for support.⁵⁶</p>	<p>(1991) World Health Organization Resolution WHO urged each National Tuberculosis Control Programme to work towards two “WHO targets by the year 2000: (1) to treat successfully 85% of detected smear-positive cases, and (2) to detect 70% of all such cases, by the introduction of an effective approach to TB control. The global status of TB control and progress</p>

⁵² Merson, 2006.

⁵⁵ Roll Back Malaria Partnership, 2008). Roll Back Malaria Action Plan.

⁵⁶ WHO, 1974.

Nations, 2001) ⁵³ (2001) UN General Assembly Special Session Declaration of Commitment on HIV/AIDS ⁵⁴	1992: WHO Ministerial Conference in Amsterdam convened by WHO endorsed the Global Strategy for Malaria Control ⁵⁷ 1995: WHO Plan of Action for Malaria Control 1995: United Nations Secretary General (through the Economic and Social Council) declared a plan of action, for preventative action against Malaria and diarrhoeal diseases in developing countries, particularly Africa -- admittedly with limited funding ⁵⁸ Preventive action and intensification of the struggle against malaria in developing countries, particularly in Africa. (1998) roll Back Malaria Partnership (rBM) was “launched by WHO, UNICEF, UNDP and World Bank with [the] goal of halving malaria incidence and mortality by 2010” ⁵⁹ and “to align global health and development ⁶⁰ advocates, raise malaria on political and development agendas and unite key stakeholders behind an ambitious but achievable strategy to end malaria worldwide. The 2000 Summit on Roll Back Malaria, held in Abuja issued the Abuja Declaration and the Plan of Action pledged to halve malaria mortality in Africa by 2010 ⁶¹	towards achieving the WHO targets were reviewed in 1997, 1998 and 1999 ⁶² . (1995) WHO established a worldwide TB surveillance and monitoring project ⁶³ (2000) The Ministerial Conference on TB & Sustainable Development 24 March 2000 issued The Amsterdam Declaration to Stop TB calling worldwide support for the World Bank and WHO towards “new momentum against tuberculosis” ⁶⁴
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⁵³ United Nations, 2001

⁵⁴ United Nations, 2001.

⁵⁷ WHO (1993). A Global Strategy for Malaria Control. Retrieved from <http://whqlibdoc.who.int/publications/9241561610.pdf>

⁵⁸ United Nations (1995). Preventive action and intensification of the struggle against malaria in developing countries, particularly in Africa. General Assembly Economic and Social Council. 18 May 1995. Retrieved from <http://www.un.org/documents/ga/docs/50/plenary/a50-180.htm>. A/50/180-E/1995/63

⁵⁹ University of California. (N.D.) Progress Fighting Malaria: A timeline. <https://www.ucsf.edu/news/2011/08/10525/progress-fighting-malaria-timeline>

⁶⁰ Roll Back Malaria. (N.D.) Key Facts, Figures and Strategies. The Global Malaria Action Plan. Retrieved from http://www.rollbackmalaria.org/gmap/GMAP_Advocacy-ENG-web.pdf

⁶¹ The Abuja Declaration and the plan of action. An extract from the African Summit on Roll Back Malaria 25 April 2000 <http://www.who.int/malaria/publications/atoz/whocdsrbm200346/en/>

⁶² Forty-Fourth World Health Assembly, Geneva, 6–16 May 1991. Resolutions and decisions. Geneva, Switzerland: World Health Organization 1991. WHA44/1991/REC/1. (Cited in: Global Tuberculosis Control: WHO Report 2000)

⁶³ Global Tuberculosis Control: WHO Report 2000 http://apps.who.int/iris/bitstream/handle/10665/63835/WHO_CDS_TB_2000.275.pdf?sequence=2

⁶⁴ Amsterdam Declaration to Stop TB http://www.stoptb.org/assets/documents/events/meetings/amsterdam_conference/decla.pdf

http://apps.who.int/iris/bitstream/handle/10665/67816/WHO_CDS_RBM_2003.46.pdf;jsessionid=1C5A61A812B2362CF877E702B519A174?sequence=1

Appendix F: Comparing Leading 10 Global Causes of Death for 2000 and 2016

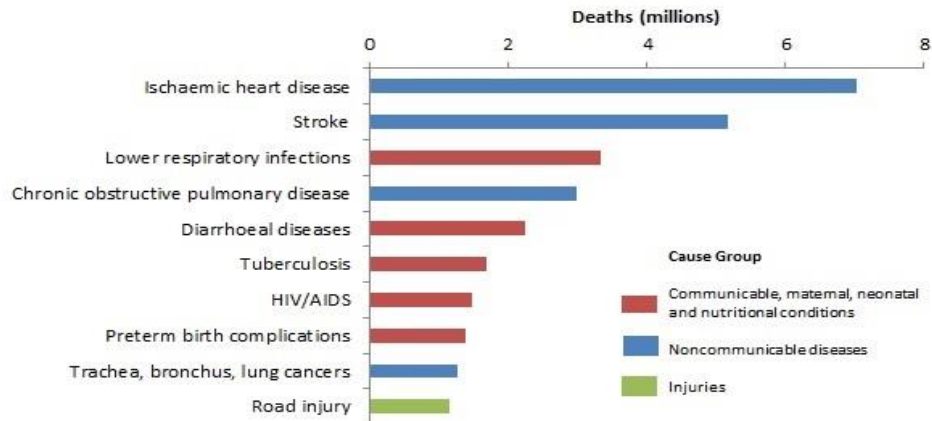


Figure F-1. Top 10 global causes of death in 2000
Source: World Health Organization, 2018a

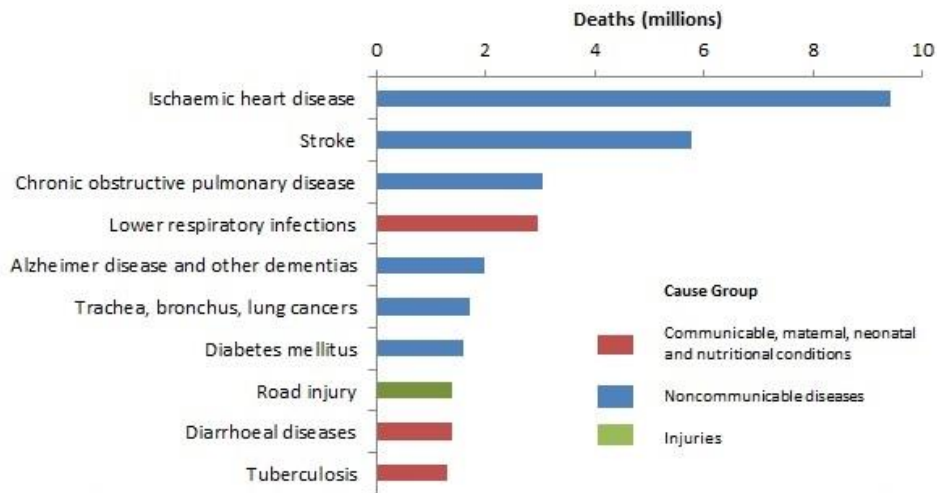


Figure F-2. Top 10 global causes of death in 2016
Source: World Health Organization, 2018a

Appendix G: Global Estimates for HIV Morbidity and Mortality, 2000 to 2016

Table G-1

Global HIV Morbidity and Mortality for 2000-2016

Year	HIV-related deaths	Estimated PLHA
2000	1,700,000	25,900,000
2001	1,900,000	27,200,000
2002	2,100,000	28,200,000
2003	2,200,000	28,900,000
2004	2,300,000	29,400,000
2005	2,300,000	29,700,000
2006	2,300,000	30,100,000
2007	2,200,000	33,200,000
2008	2,100,000	33,500,000
2009	2,000,000	34,000,000
2010	1,900,000	34,400,000
2011	1,800,000	34,900,000
2012	1,600,000	35,300,000
2013	1,500,000	35,000,000
2014	1,200,000	36,900,000
2015	1,100,000	36,700,000
2016	1,000,000	36,700,000

Sources: UNAIDS, 2013a; UNAIDS 2013b; UNAIDS, 2014b; UNAIDS, 2015; UNAIDS, 2017

Appendix H: HIV Statistics by UNAIDS Region at the End of 2000

Table H-1

Regional HIV Statistics at the end of 2000

Region	Epidemic started	Adults and children living with HIV/AIDS	Adult prevalence rate^a
Sub-Saharan Africa	Late 1970s, early 1980s	25.3 million	8.8%
North Africa and Middle East	Late 1980s	400,000	0.2%
South & South-East Asia	Late 1980s	5.8 million	0.56%
East Asia & Pacific	Late 1980s	640,000	0.07%
Latin America	Late 1970s, early 1980s	1.4 million	0.5%
Caribbean	Late 1970s, early 1980s	390,000	2.3%
Eastern Europe & Central Asia	Early 1990s	700,000	0.35%
Western Europe	Late 1970s, early 1980s	540,000	0.24%
North America	Late 1970s early 1980s	920,000	0.6%
Australia & New Zealand	Late 1970s, early 1980s	15,000	0.13%
Total		36.1 million	1.1%

Notes

^a The proportion of adults (15–49 years of age) living with HIV/AIDS in 2000.

Source: UNAIDS, 2000.

Appendix I: Comparison of HIV Prevalence (Old and New Estimates)

Table I-1

Comparison of HIV Prevalence (Old Estimates)

Year	Adult Prevalence Rate	
	Sub-Saharan Africa	Caribbean
2000 ¹	8.80%	2.30%
2001 ²	8.4	2.2
2002 ³	8.8	2.4
2003 ⁴	7.5	2.3
2004 ⁵	7.4	2.3
2005 ⁶	7.2	1.6
2006 ⁷	5.9	1.2
2007 ⁸	5	1.0
2008 ⁹	5.2	1.0
2009 ¹⁰	5.0	1
2010 ¹¹	5.0	0.9
2011 ¹²	4.9	1.0
2012 ¹³	5.8	1.3

¹UNAIDS, World Health Organization (2000).

²UNAIDS, World Health Organization (2001).

³UNAIDS, World Health Organization (2002).

⁴UNAIDS (2004a).

⁵UNAIDS, World Health Organization (2004).

⁶UNAIDS, World Health Organization (2005).

⁷UNAIDS, World Health Organization. (2006).

⁸UNAIDS, World Health Organization. (2007).

⁹UNAIDS, World Health Organization. (2009).

¹⁰UNAIDS (2010).

¹¹UNAIDS (2011).

¹²UNAIDS (2012)

¹³UNAIDS (2013).

Table I-2
Comparison of HIV Prevalence (2018-Revised Estimates)

Year	Revised Adult HIV Prevalence	
	Sub-Saharan Africa	Caribbean
2000	4.7	1.3
2001	4.7	1.3
2002	4.6	1.3
2003	4.6	1.3
2004	4.5	1.3
2005	4.4	1.3
2006	4.2	1.3
2007	4.1	1.3
2008	4.1	1.3
2009	4	1.2
2010	3.9	1.2
2011	3.8	1.2
2012	3.8	1.2
2013	3.7	1.2
2014	3.7	1.2
2015	3.6	1.2
2016	3.5	1.2

Appendix J: Political Groupings and Regional Institutions Coordinating the HIV

Response in the Caribbean

Table J-1

The Caribbean: Political Groupings and Regional Institutions Involved in Coordinating the Response to HIV (Countries in the study are in bold font)

Country	Membership status							Language	Income classification
	ACS	CARICOM	OECS	CARPHA	PANCAP	PAHO	UNAIDS Global**		
Antigua and Barbuda*	#	#	#	#	#	#	x	E	H
Anguilla	x	*	*	#	x	x	x	E	N
Aruba	*	x	x	#	#	#	x	D	H
(The) Bahamas	#	#	x	#	#	#	#	E	H
Barbados	#	#	x	#	#	#	#	E	H
Belize	#	#	x	#	#	#	x	E	UM
Bermuda	x	*	x	#	#	#	x	E	H
Bonaire	x	x	x	x	x	x	x	D	N
British Virgin Islands	x	*	*	#	x	x	x	E	H
Cayman Islands	x	*	x	#	x	x	x	E	H
Colombia	#	x	x	x	x	#	x	S	UM
Costa Rica	#	x	x	x	x	#	x	S	UM
Cuba	#	x	x	x	x	#	#	S	UM
Curacao	*	x	x	x	#	x	x	D	H
Dominica*	#	#	#	#	#	#	x	E	UM
Dominican Republic	#	x	x	x	#	#	#	S	UM
El Salvador	#	x	x	x	x	#	x	S	LM
Grenada*	#	#	#	#	#	#	x	E	UM

Country	Membership Status							Official Language	Income classification
	ACS	CARICOM	OECS	CARPHA	PANCAP	PAHO	UNAIDS Global**		
Guadeloupe	*	x	x	x	#	#	x	F	N
Guatemala	#	x	x	x	x	#	x	S	LM
Guyana	#	#	x	#	#	#	x	E	UM
Haiti	#	#	x	x	#	#	#	F	L
Honduras	#		x	x	x	#	x	S	LM
Jamaica	#	#	x	#	#	#	#	E	UM
Martinique	*	x	x	x	x	#	x	F	N
Mexico	#	x	x	x	x	x	x	S	UM
Montserrat	x	#	#	#	#	x	x	S	N
Nicaragua	#	x	x	x	x	#	x	S	LM
Panama	#	x	x	x	x	#	x	S	UM
Puerto Rico	x	x	x	x	x	#	x	S	N
St Kitts and Nevis*	#	#	#	#	#	#	x	E	H
St. Lucia*	#	#	#	#	#	#	x	E	UM
Saba	x	x		#	x	x	x	E	N
Saint Bartholomy	x	x	x	x	x	x	x	F	N
Saint Maarten (French Territory)	*	x	x	#	x	x	x	F	N
Saint Eustatius	x	x	x	#	x	x	x	D	N
Saint Martin/Saint Maarten (Dutch Territory/French Territory)	x	x	x	x	x	x	x	D/F	N

Country	Membership Status							Language	Income classification
	ACS	CARICOM	OECS	CARPA	PANC AP	PAHO	UNAIDS Global**		
St Vincent and the Grenadines*	#	#	#	#	#	#	x	E	UM
Suriname	#	#	x	x	#	#	x	D	UM
Trinidad and Tobago	#	#	x	#	#	#	#	E	H
Turks and Caicos Islands	x	*	x	#	x	#	x	E	H
United States Virgin Islands	x	x	x	x	x	#	x	E	N
Venezuela	#	x	x	x	x	x	x	S	UM

**= Included in estimates

= Full Member

*= Associate Member

X= No membership

Language abbreviations

E = English D= Dutch F= French S= Spanish

Source of membership and affiliation information for:
 Association of Caribbean States (ACS): (ACS, n.d.).
 Caribbean Community (CARICOM): CARICOM (n.d.-a)
 OECS: OECS (n.d.)
 PAHO. Pan American Health Organization. (n.d.-a)
 CARPHA Membership: CARPHA (n.d.)
 UNAIDS: <http://www.unaids.org/en/regionscountries/countries>
 Income classification as of December 2018
http://data.worldbank.org/about/country-classifications/country-and-lending-groups#Low_income
 World Bank's income classification: World Bank (2018b)

H= High-income according to World Bank's income classification
 UM = Upper-Middle-income according to World Bank's income classification
 M=Middle-income according to World Bank's income classification
 L= Low-income according to World Bank's income classification
 N= Not Assessed in the World Bank's income classification

For the 2019 fiscal year using the World Bank Atlas method, high-income economies are those with a GNI per capita of \$12,056 or more
 Upper-middle-income economies are those with a GNI per capita between \$3,896 and \$12,055;
 Lower-middle-income economies are those with a GNI per capita between \$996 and \$3,895;
 low-income economies are defined as those with a GNI per capita in 2017
 (From <https://datahelpdesk.worldbank.org/knowledgebase/articles/906519>)