NATIONAL PARTNERSHIP FOR ACTION
to End Health Disparities

Improving Health Data Infrastructure for the U.S. Virgin Islands

Region II Health Equity Council

IMPROVING HEALTH DATA INFRASTRUCTURE FOR THE U.S. VIRGIN ISLANDS

REGIONAL HEALTH EQUITY COUNCIL II
COMMITTEE ON RESEARCH, EVALUATION AND DATA

PROGRESS REPORT

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ACKNOWLEDGEMENTS

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INTRODUCTION

Vital statistics data on access to prenatal care, maternal risk factors, infant mortality, cause of death, life expectancy and other indicators are the foundation of population health policy and management. Reliable data are needed to track overall population health; plan, implement and evaluate health and social services for children, families and adults; and establish health policy at national, state and local levels.

Region II of the Regional Health Equity Council (RHEC) covers New York, New Jersey, the Commonwealth of Puerto Rico and the U.S. Virgin Islands (USVI). The New York and New Jersey Offices of Minority Health (OMH) serve as statewide resources for eliminating health disparities. Significant progress has been made in collecting and reporting health data for Puerto Rico, but major gaps persist. Of the four Region II jurisdictions, the USVI health data infrastructure is the least developed.

During the 2013 RHEC II Technical Assistance meeting, the Committee on Research, Evaluation and Data agreed to collaborate to improve the USVI health data infrastructure. The Committee was uniquely positioned to implement this project because the RHEC membership includes active participation by several USVI representatives.

Committee Members

- Dr. Gloria Callwood (Associate Professor of Nursing and Principal Investigator/Director of the Caribbean Exploratory NIMHD Research Center, School of Nursing, UVI)
- Dr. Noreen Michael (Research Director, Caribbean Exploratory NIMHD Research Center, School of Nursing, UVI)
- Ms. Shaniece Charlemagne (Director of Primary Care, USVI Department of Health)

RHEC II Members

- Mr. Moleto Smith (Executive Director, St. Thomas East End Medical Center Corporation (former Deputy Commissioner, VI Department of Human Services)
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Former RHEC II Co-Chair

- Ms. Gwendolyn Powell (Executive Director of Work-Able, Inc., a USVI non-profit service provider)

All USVI RHEC II members contributed their expertise and insights to this project.

The Committee developed a work plan with three key goals:

- Identify datasets and data sources that report on the USVI population;
- Identify data gaps and challenges in the USVI data collection system; and
- Develop recommendations to federal agencies on ways to improve the health data infrastructure and information system for the US.

OMH supported three Emerging Health Professionals (EHPs) to assist the Committee: Dakota Cintron, Alexis Diaz-Ramos and Gisela Medina-Martinez. Dr. Callwood, Dr. Michael and Ms. Charlemagne supervised the EHPs during the summers of 2013 and 2014. This report summarizes the research findings of the EHPs, but the results were supplemented with online research conducted by committee members, as well as information and insights shared by USVI committee representatives.

OVERVIEW OF THE USVI

USVI is twice the size of Washington D.C. and covers 346 square miles. Based on 2010 census data, the three main USVI islands – St. Croix, St. Thomas and St. John – had a collective population of 106,405. These data represented a 2% decrease in the population from the 2000 census. Of the total population, approximately 76% is black and 15% is white. The islands are an organized, unincorporated U.S. territory with policy relations between the Virgin Islands and the United States under the jurisdiction of the Office of Insular Affairs, U.S. Department of the Interior. USVI residents who are U.S. citizens do not vote in U.S. presidential elections. The governor is democratically elected for four years and serves as the USVI chief executive.

The primary economic activities of the USVI are tourism, trade and other services. Cruise ship passengers account for the majority of nearly 3 million tourists who visit USVI annually. The agriculture sector is small, with most foods being imported. The manufacturing sector primarily is rum distillery, pharmaceuticals, watch assembly and electronics. Federal programs and grants totaled $241.4 million in 2013 and contributed 19.7% of the territory's total revenues. A large oil refinery in St. Croix closed in 2012 after more than 45 years of operation. Compared to the national unemployment rate of 5.6%[1], the unemployment rate on the island was 13% in 2014.

The USVI Department of Health (DOH) functions as both the island's regulatory agency and public health agency. DOH has direct responsibility for conducting preventive medicine programs, including special programs for maternal/child health (MCH), family planning, environmental sanitation, mental health, and substance abuse prevention. DOH also is

[1] *The World Factbook* 2013-14. Washington, DC: Central Intelligence Agency, 2013. Accessed on September 15, 2015 at https://www.cia.gov/library/publications/the-world-factbook/index.html

responsible for health promotion and protection, regulation of healthcare providers and facilities, policy development and planning, and maintenance of vital statistics of the territory's population.

The territory has two public hospitals and two Federally Qualified Health Centers. DOH also has several clinics in St. Croix and St. Thomas that offer a wide range of services: community health, MCH, communicable diseases, mental health, methadone, Infants and Toddlers Program (speech pathology, physical/occupational/developmental therapy, behavioral health, and ophthalmology), immunization, and family planning. Of approximately 180 healthcare providers as of 2011, many receive salaries from hospitals or clinics and also operate private practices.[2]

Current data show that approximately 29% of the USVI population is uninsured. The USVI government has a workforce of approximately 12,000 employees and is the largest employer in the territory. The government provides health insurance to its employees through CIGNA. The Medical Assistance Program, the island's Medicaid program, insures approximately 8,500 residents. USVI, Puerto Rico and other U.S. territories were excluded from participating in the Affordable Care Act health insurance exchange. This exclusion and the cap on Medicaid expenditures present significant healthcare access barriers for USVI residents.

A task force was convened in 2001 with representation by key DOH personnel, experts from multiple public and private agencies, and stakeholders from community-based organizations to develop DOH's first strategic plan. *Healthy People 2010* was used as a model in this effort. The task force identified 28 health concerns and disparities in the USVI. The leading health concerns centered on issues of access to quality health services for 1) heart disease and stroke, 2) cancer, 3) diabetes, and 4) HIV infection.[3] The task force's efforts led to the development of DOH's comprehensive strategic plan, *Healthy Virgin Islands 2010*. DOH currently is updating the strategic plan.

USVI received a federal grant of $1 million in 2010 to improve the health information technology infrastructure in the territory. The aim of the project is to enable "meaningful use" of electronic health records among healthcare providers and facilities.

Publications of scholarly research on health disparities and health concerns among USVI residents have been limited to date. In 2004, the National Institutes of Health, National Center on Minority Health and Health Disparities (NIH/NCMHD) awarded a three-year grant to establish "The Caribbean EXPORT Center for Research and Education in Health Disparities." The Export Center provided support to UVI faculty to develop sufficient capacity and a solid

[2] U.S. Virgin Islands Department of Health, Virgin Islands Health Information Exchange, Strategic and Operational Plan, January 15, 2011.

[3] Gloria B. Callwood, PhD, RN, Doris Campbell, PhD, ARNP, FAAN, Faye Gary, EdD, FAAN, and Michael L. Radelet, PhD. Health and health care in the US Virgin Islands: challenges and perceptions. ABNF J. 2012, Winter; 23(1): 4–7. Accessed on September 16, 2015 at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3573759/

infrastructure to begin to investigate and address health issues and disparities in the USVI. In October 2007, a five-year NCMHD grant was awarded to establish the "Caribbean Exploratory Research Center" (CERC) to continue and expand this initiative. CERC has published several journal articles related to health and health disparities in the USVI. The Center received a second five-year continuation grant in 2012 and will be funded through 2017 to continue its health disparities research.

WHAT DATA ARE CURRENTLY AVAILABLE ON THE USVI?

The Committee on Research, Evaluation, and Data documented the current availability of USVI data on the following areas related to health status, health behaviors/outcomes and social determinants of health:

- Population (total population, gender, age, race/ethnicity)
- Education (level of education attained, high school graduation, dropout rates)
- Jobs (labor force participation, unemployment)
- Income (income levels, per capita income, median family income, individuals in poverty, children in poverty, children in families receiving SNAP)
- Access to care (health insurance coverage, health screening, childhood immunization)
- Mortality and diseases (infant mortality, low birth rate, mortality rates for major diseases)
- Health status (self-reported health status, teen birth rate, pre-term births, flu shots, overweight and obesity)
- Violence and safety (homicide, firearm safety, school and neighborhood safety, youth attempted suicide)
- Behavioral health (smoking, alcohol use, physical activity, fruit and vegetable consumption)
- Oral health (use of dental services, adults with teeth extraction)

WHAT IS THE HEALTH PROFILE OF THE USVI?

The USVI health profile is presented within a population health framework (Centers for Disease Control and Prevention (CDC), 2013). USVI population and demographic data are presented first, followed by available data on health outcomes and health determinants metrics recommended for inclusion when reporting on community health assessments (CDC, 2013). The data presented are comparative and include indicators for other Region II jurisdictions (Puerto Rico, New Jersey

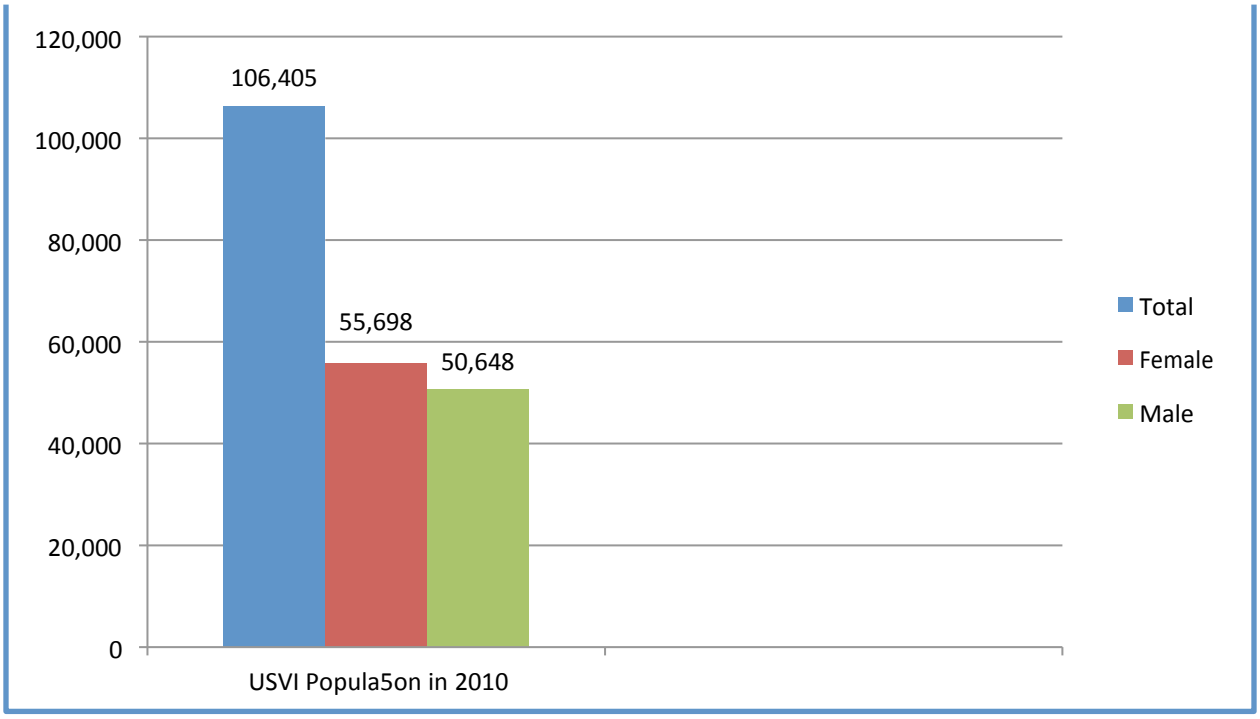
and New York), other territories and the nation. Both federal and local data sources were used in the compilation of the information presented below.

Demographic and Social Determinants of Health Indicators

Health outcomes are influenced by factors beyond healthcare, such as demographics and social determinants of health (SDOH)[i]. It is well documented that these factors shape the way in which persons live, work, learn and play, which in turn impact health and health outcomes[ii]. Surveillance data provide valuable information that can be used to monitor and evaluate population health outcomes. Understanding the demographics and SDOH indicators is vital to improving community health by allowing public health professionals to create targeted approaches to address the factors that shape an individual's health status.

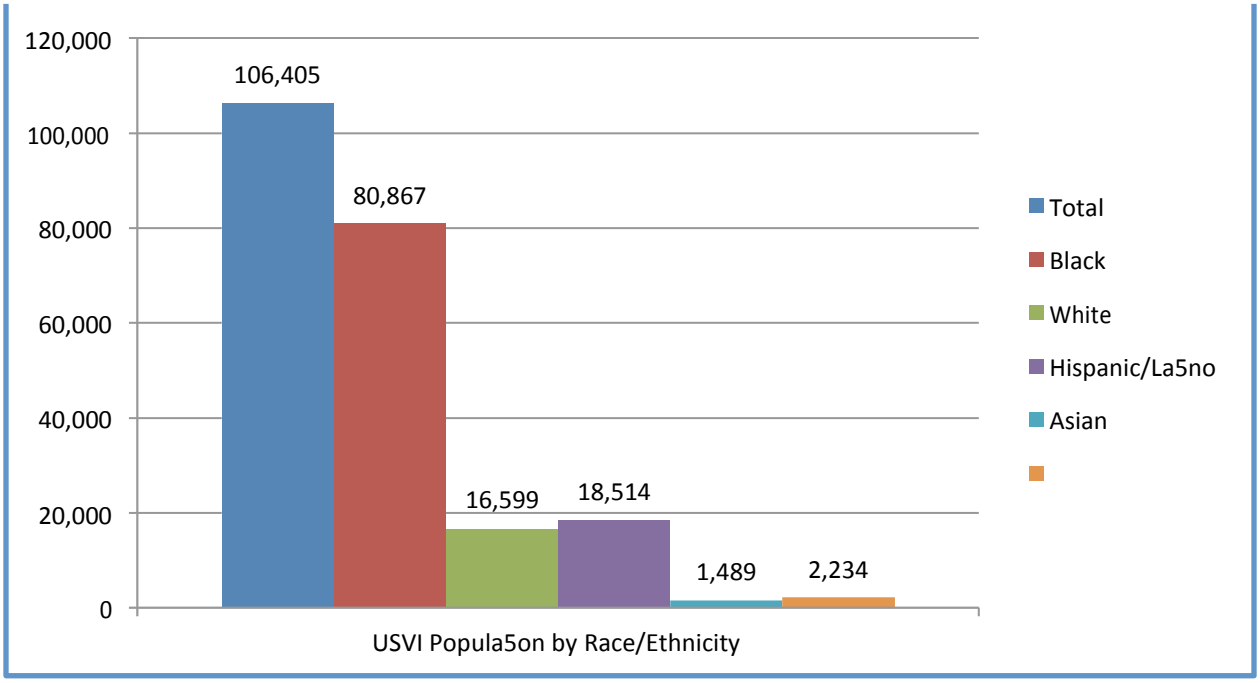
Gender, Race/Ethnicity, Age

USVI Population by Gender



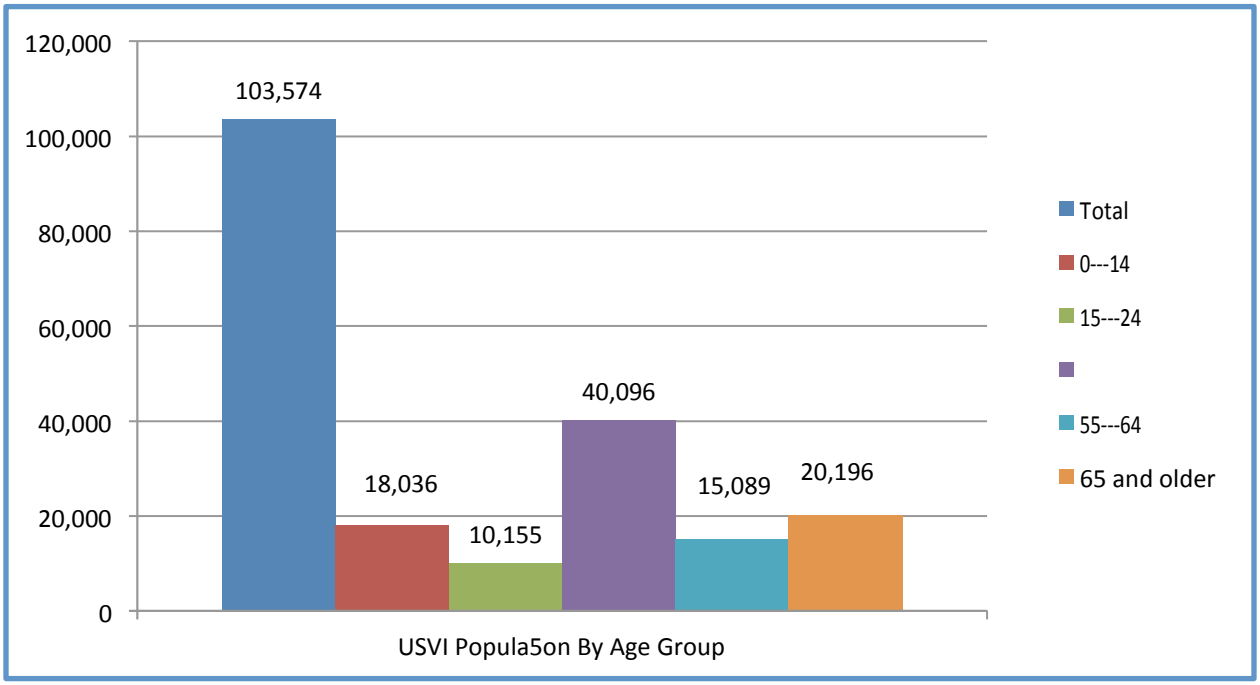
Source: U.S. Census Data 2010

USVI Population by Race/Ethnicity



Source: U.S. Census Data 2010

USVI by Age

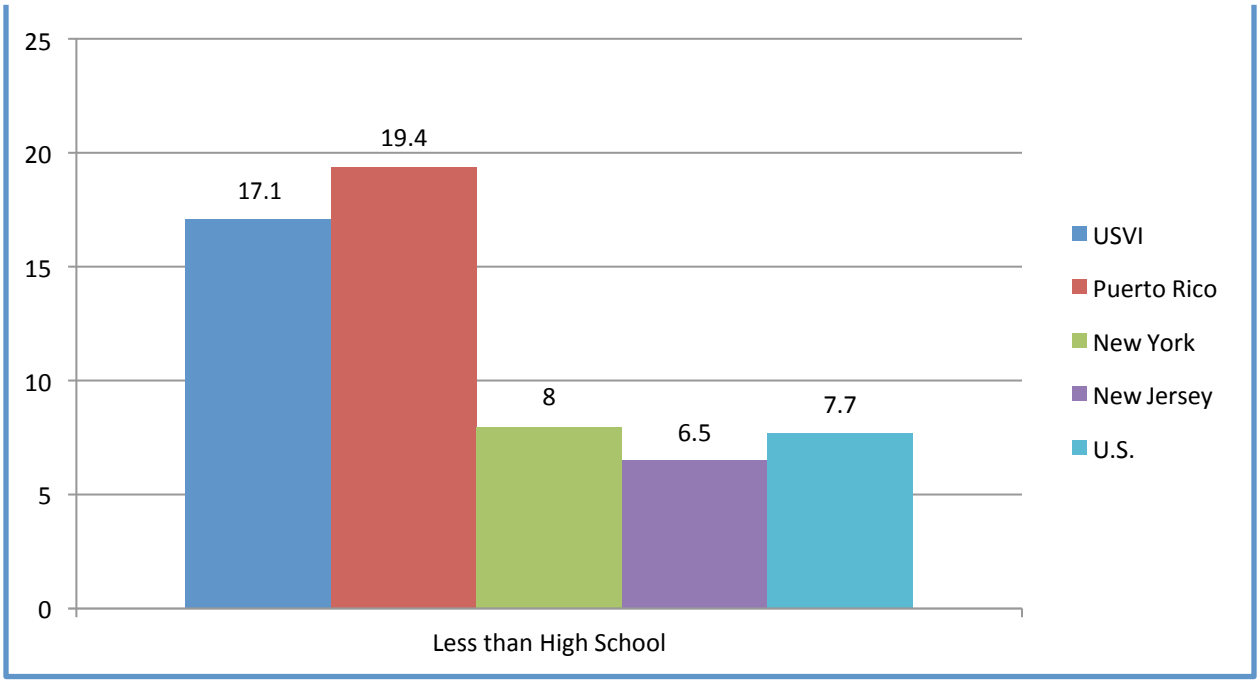


Source: The World Factbook, Central Intelligence Agency, https://www.cia.gov/library/publications/the-world-factbook/geos/vq.html, accessed on July 14, 2016.

Education

It is well documented that one's level of education impacts health[iii]. The research shows that persons with higher levels of educational attainment live longer and healthier lives than those with less education[iv].

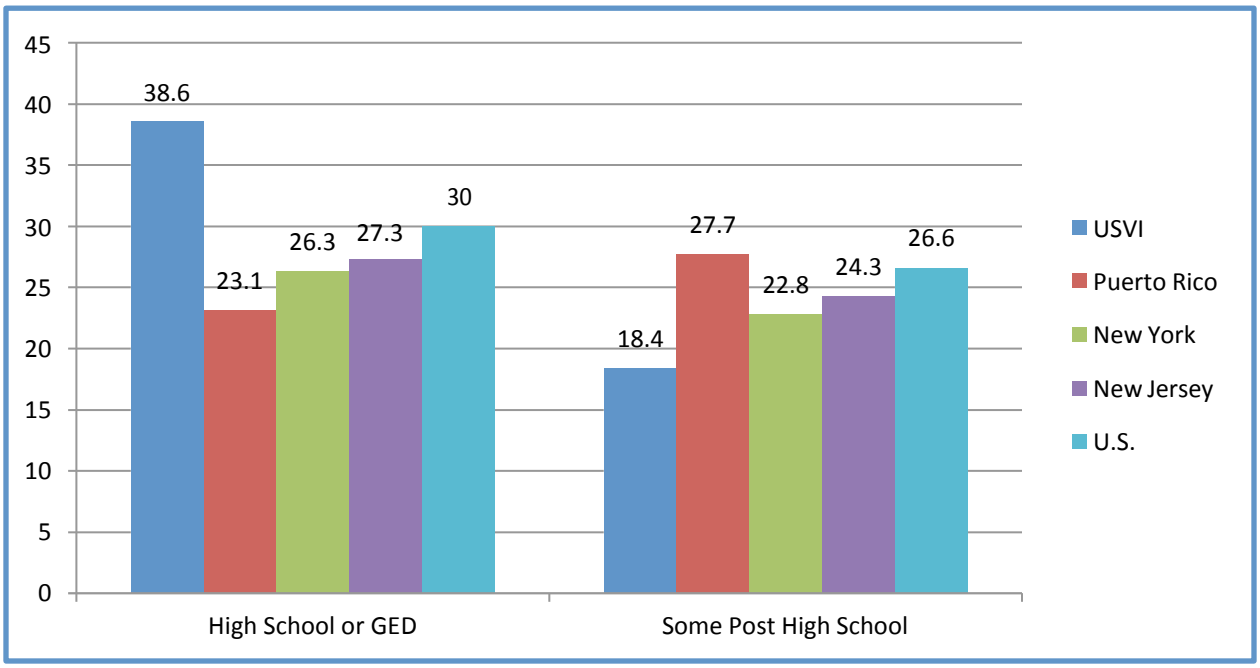
Figure 1, Percent of Population with Less than a High School Education



Source: BRFSS 2010

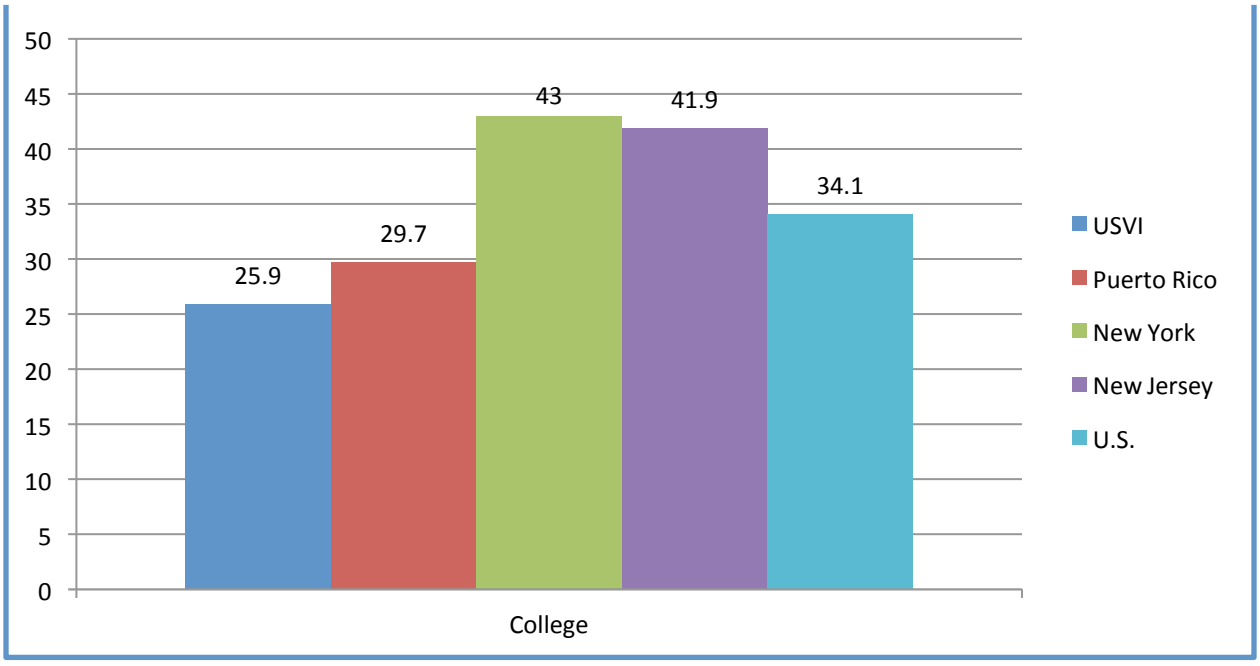
Compared to New York, New Jersey and the nation, Puerto Rico (17.1%) and USVI (19.4%) have higher percentages of residents with less than a high school education. Most notably, 2 in 10 adults do not have a high school diploma. These data suggest that residents in these territories are less likely to complete or attain a high school diploma or college degree. These findings also have implications for health literacy, health outcomes and health disparities for the population.

Figure 2, Percent of Population Completed High School, GED, or post High School Education



Source: BRFSS 2010

Figure 3, Percent of Population Completed College

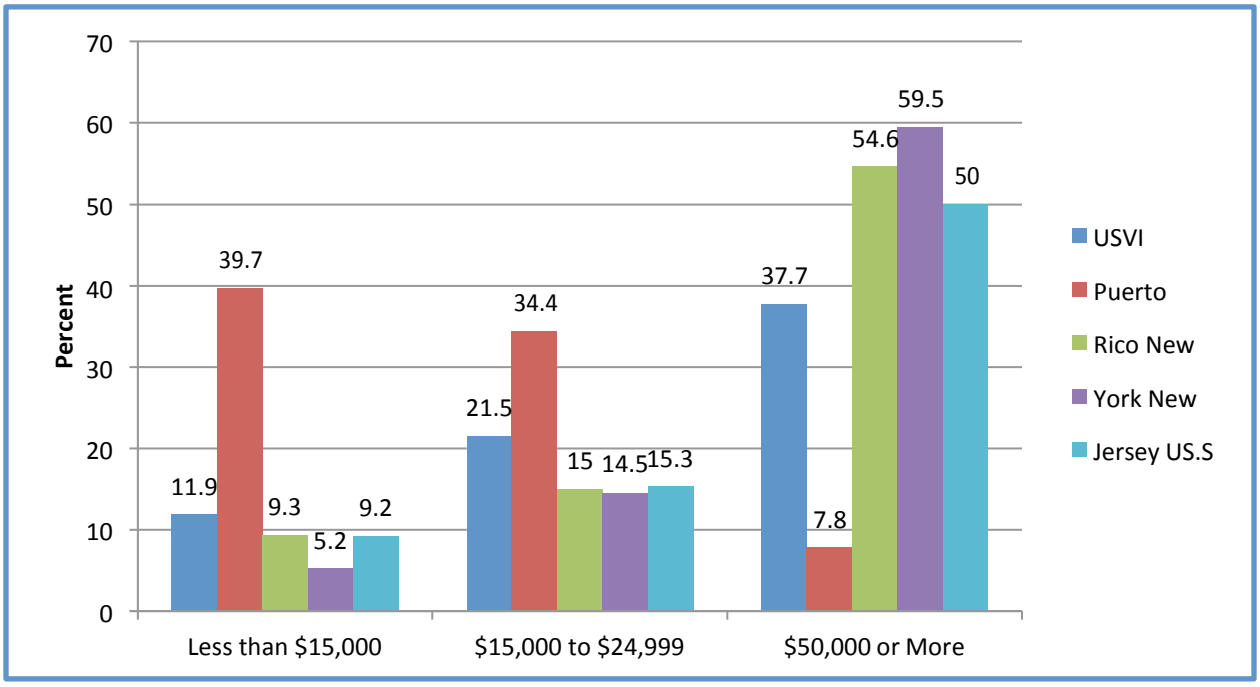


Source: BRFSS 2010

Of USVI adults, approximately 4 in 10 have a high school diploma or GED certificate, while just under 1 in 5 complete some post-high school education in Region II. USVI has the highest percentage of high school graduates and those who completed their GED (38.6%) and the lowest percentage of individuals who have completed college (25.9%).

Income

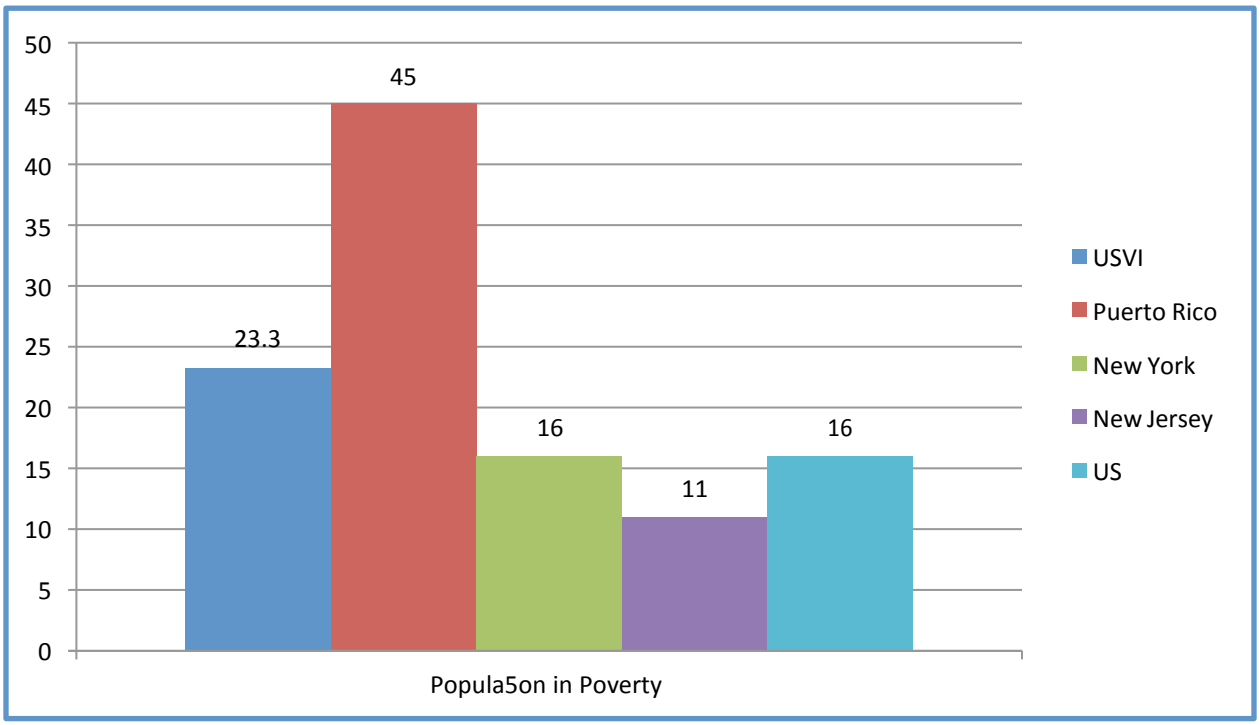
Figure 4, Annual Household Income



Source: BRFSS 2010

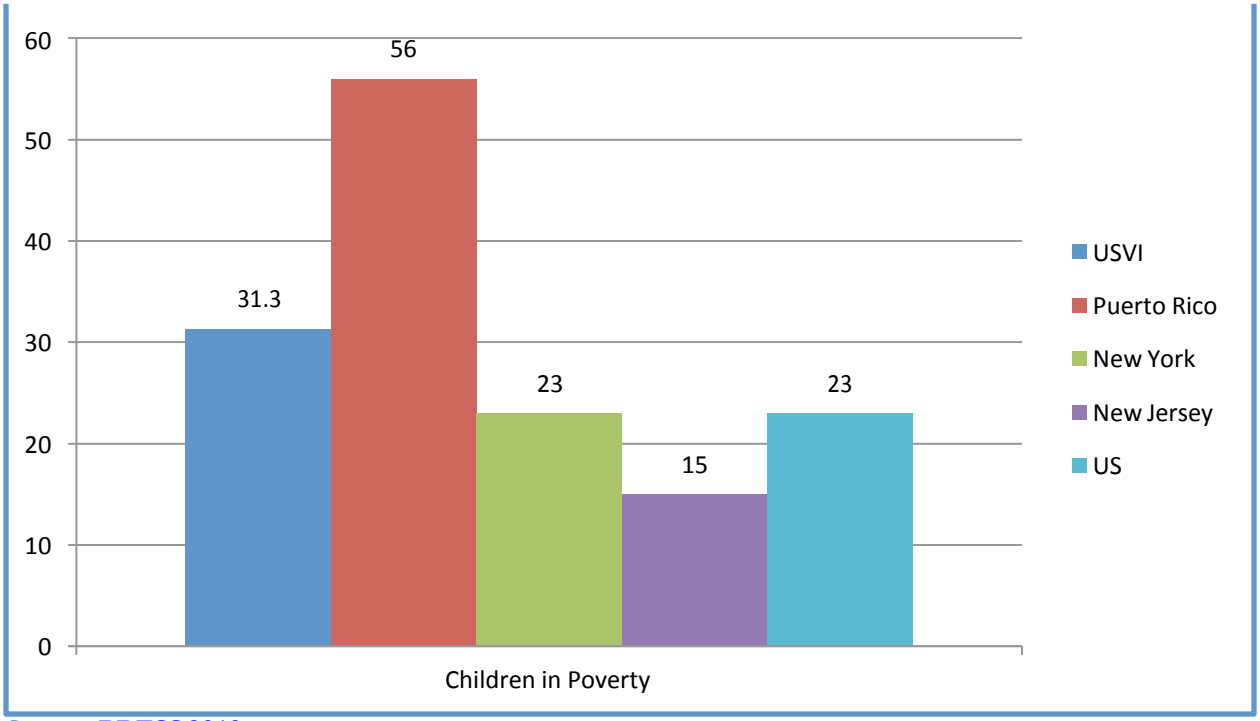
Puerto Rico has the highest percentage of households with an annual income of less than $25,000, which is more than 2-4 times higher than that of the two Region II states or the total U.S. rate. Particularly in Puerto Rico, the very high percentage of households at the lowest income level (less than $15,000 per year) and extremely low percentage of those with higher income levels ($50,000 or more per year) are much more than expected. The percentage of households with an annual income of $15,000 or less in USVI is only slightly more than those in New York and the United States.

Figure 5, Percent of Population Living in Poverty



Source: BRFSS 2010

Figure 6, Percent of Children Living in Poverty

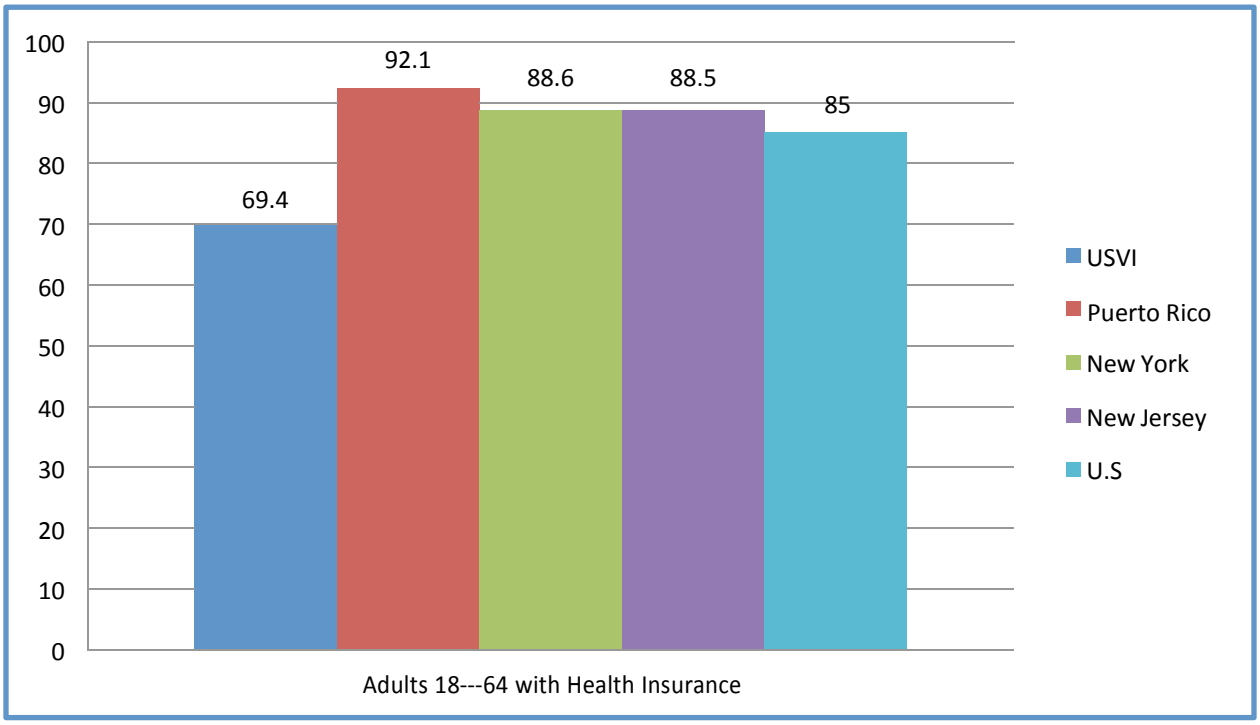


Source: BRFSS 2010

The percentages of populations and children living in poverty, defined as having household incomes at or below 100% of Federal Poverty Level, are high in Puerto Rico and more than 2-3 times higher than the percentage for other parts of Region II or the national percentage. In USVI, 31.3% of the children live in poverty, which is more than double the percentage in New Jersey, but lower than that of Puerto Rico.

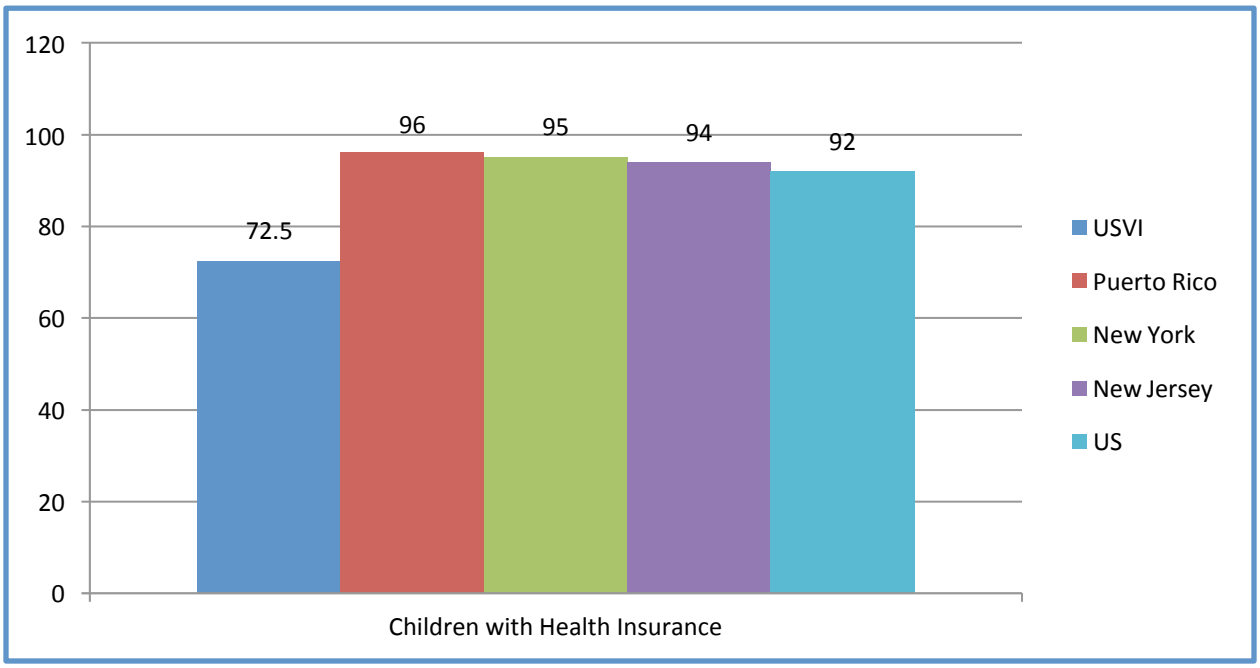
Insurance

Figure 7, Percent of Adults with Health Insurance Coverage



Source: BRFSS 2010

Figure 8, Percent of Children with Health Insurance Coverage



Source: BRFSS 2010

Populations with health insurance coverage include those covered by 1) private/commercial health plans (employment-based or direct purchase), 2) public/government insurance (Medicaid, Medicare and Military healthcare), and 3) both private and public insurance. The percentage of USVI residents with any healthcare coverage, both adults and children, is lower than other parts of Region II and the national rate, denoting a very large number of uninsured populations. Given the demographics of USVI residents, many uninsured individuals might be eligible for public government-sponsored health coverage programs, but remain uninsured due to multiple issues and barriers. This seems to be an urgent unmet need that requires a widespread and innovative outreach program based on identified needs and extensive application assistance strategies to maximize enrollment of all eligible uninsured individuals in a health insurance plan.

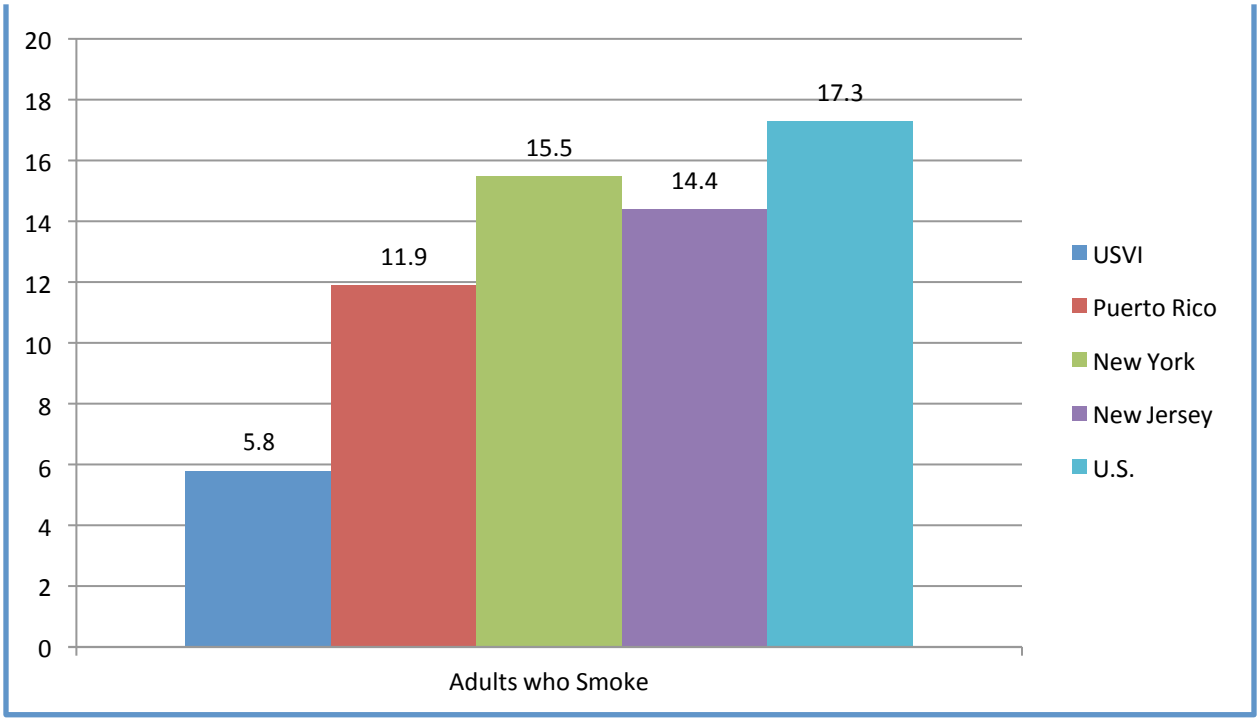
Health Outcomes Indicators

Health outcomes include "being alive; functioning well mentally, physically, and socially; and having a sense of well-being[v]." Understanding the health behaviors of a population can help public health officials to target preventive care and interventions that address potential health risks. Tobacco use and binge drinking can result in a number of chronic diseases, such as lung cancer and heart disease. The lack of preventive care can lead to missed opportunities to diagnose and treat an otherwise manageable disease[vi]. The following section describes metrics for health behaviors that can impact health outcomes and examines health outcomes that can affect morbidity (quality of life) and mortality (death).

Health Behaviors

Substance Use

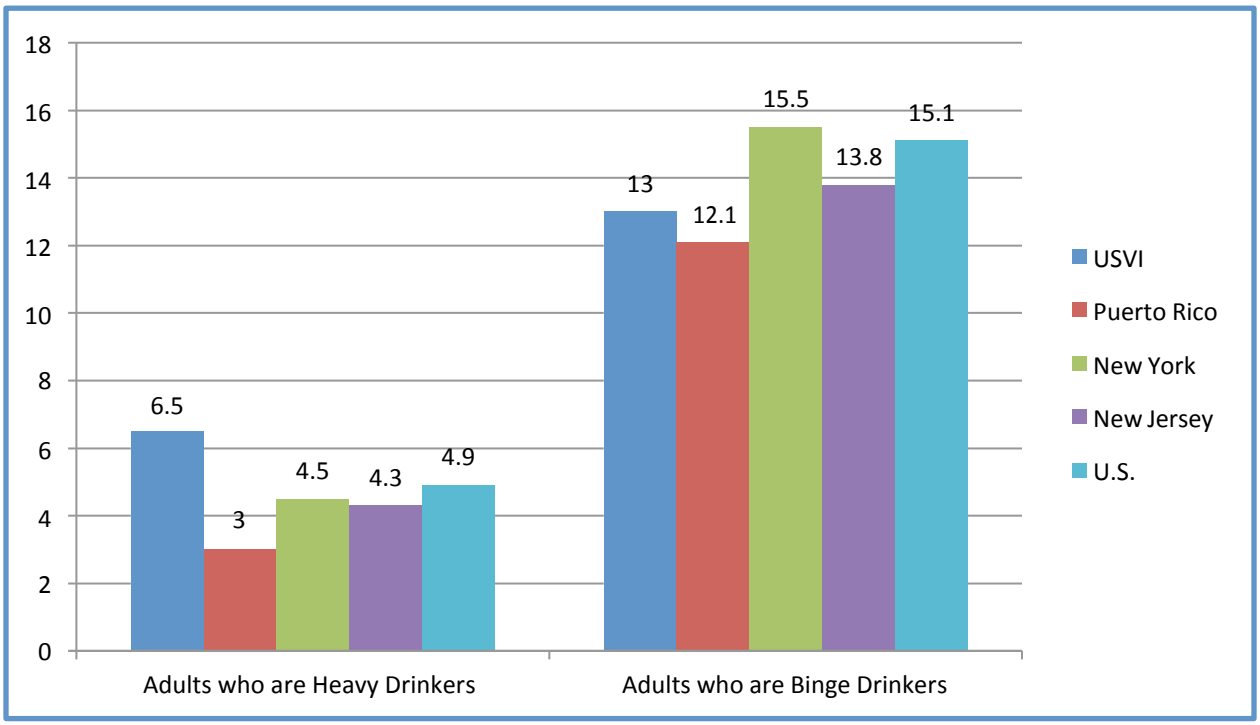
Figure 9, Percent of Adults who are Current Smokers



Source: BRFSS 2010

"Current smokers" are defined as persons who reported smoking at least 100 cigarettes during their lifetime and who, at the time of their participation in a survey about this topic, reported smoking every day or some days[vii]. The percent of adults who are current smokers in USVI is lower than those in Puerto Rico, New York, New Jersey and the United States.

Figure 10, Percent Adults who are Heavy or Binge Drinkers

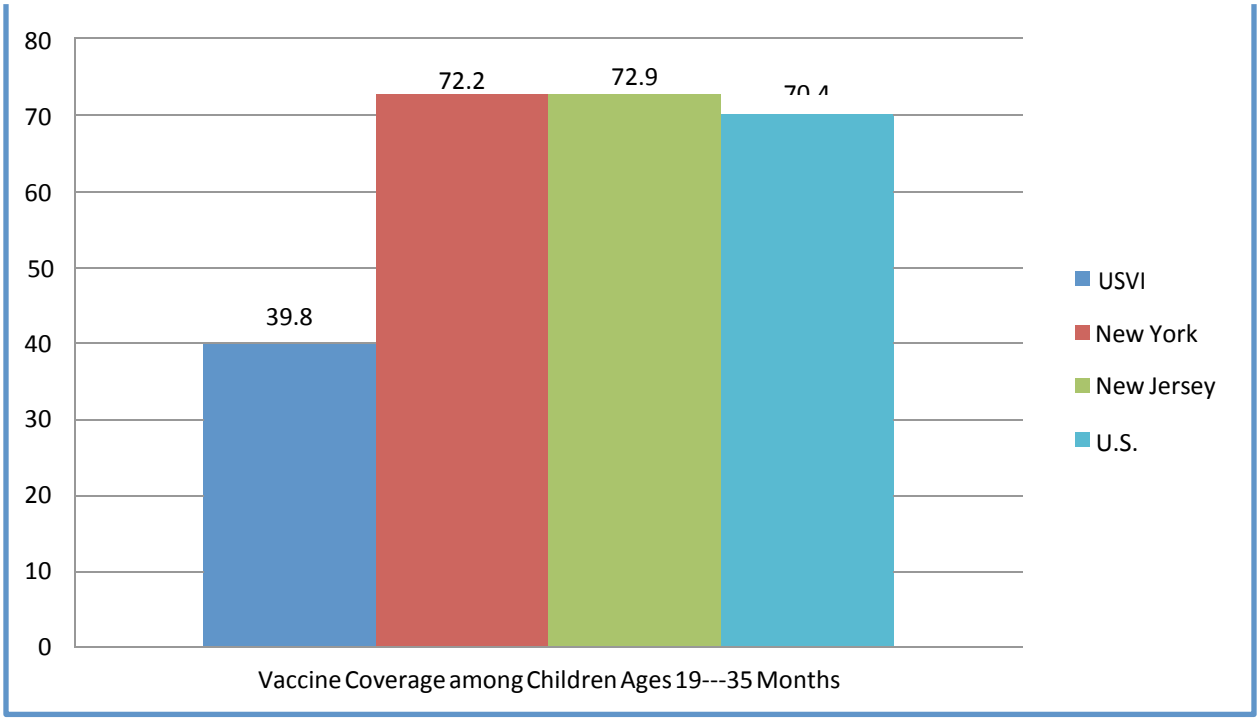


Source: BRFSS 2010

Excessive alcohol use includes heavy drinking (15 drinks or more per week for men, 8 drinks or more per week for women) and binge drinking (5 or more drinks on a single occasion for men, 4 or more drinks on a single occasion for women)[viii]. USVI has the highest percent of adults who are heavy drinkers in comparison to Puerto Rico, New York, New Jersey and the United States. Adult binge drinking in USVI is higher than in Puerto Rico, but lower than in New York, New Jersey and the United States.

Preventive Screenings and Immunizations

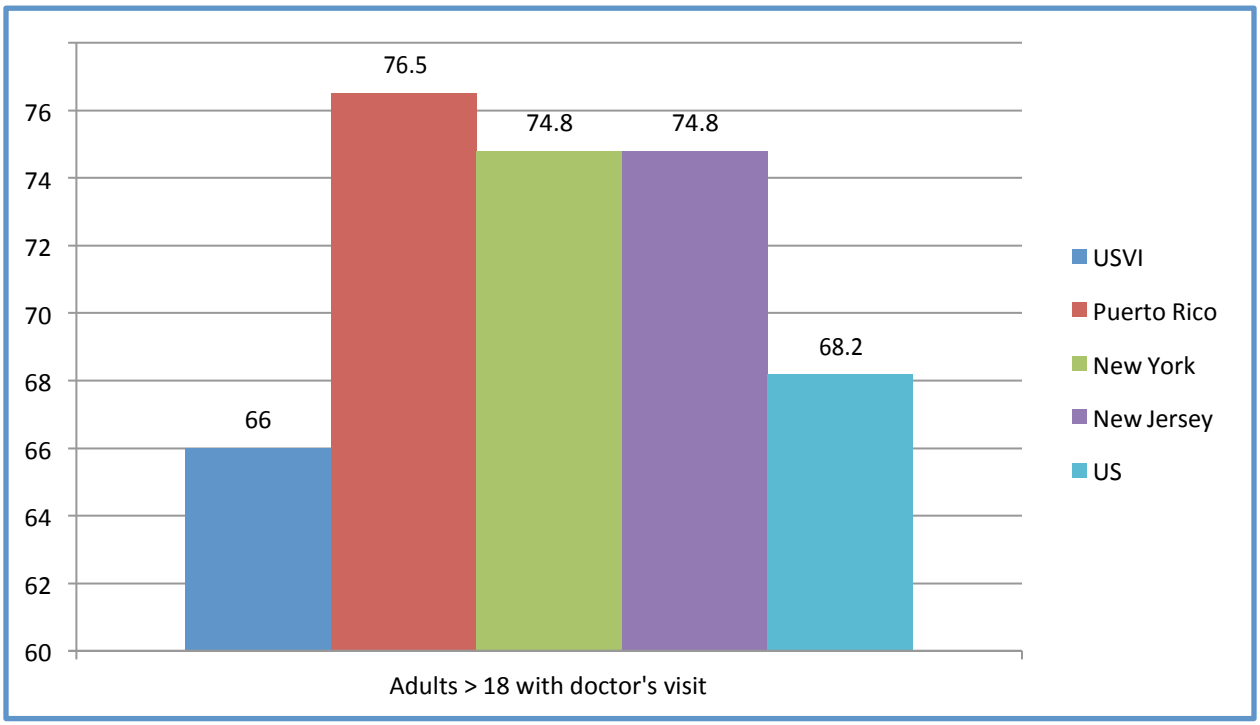
Figure 3, Percent Vaccination Coverage among Children Aged 19---35 Months – [Combined Vaccination Series]



Source: National Immunization Survey 2013. No data reported for Puerto Rico.

The reduction in morbidity and mortality associated with vaccine-preventable diseases in the United States has been described as one of the greatest public health achievements of the 21st century[ix]. A wide variation in vaccine coverage for children exists in Region II. The vaccine coverage rate for USVI is 50% lower than the coverage rate for New York and New Jersey.

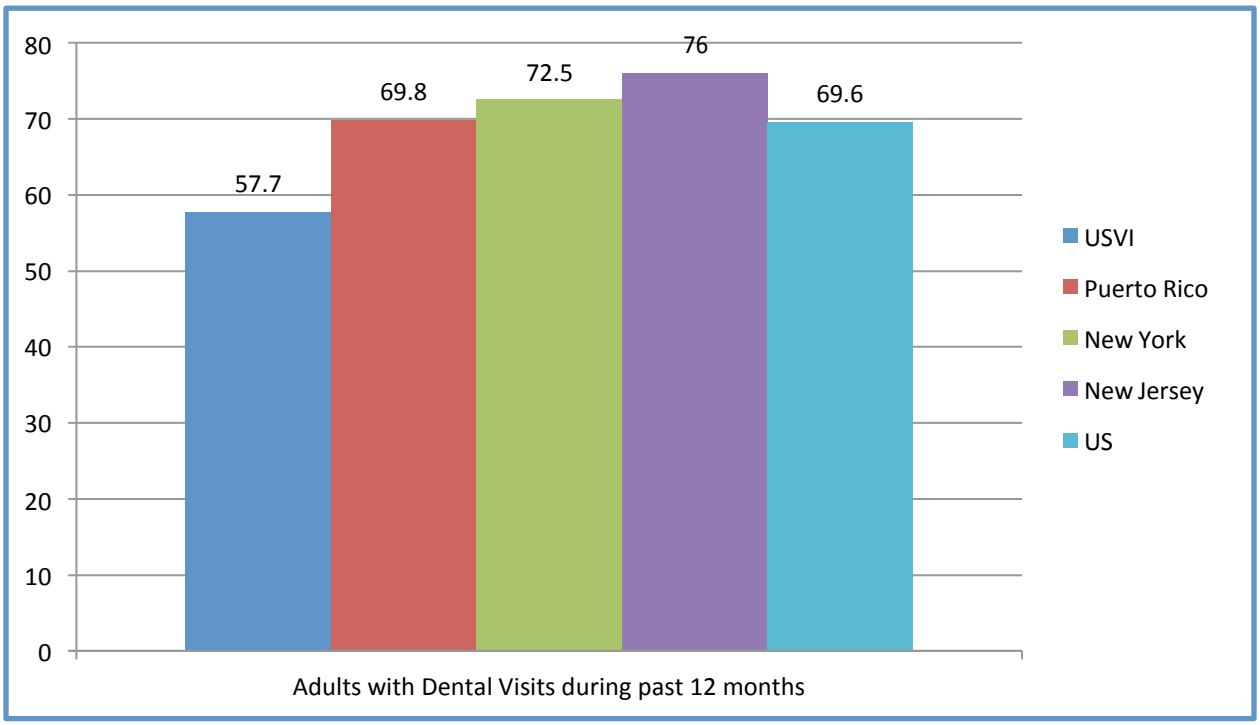
Figure 4, Percent Adults with Doctor's Visit for Routine Care during Past 12 Months



Source: BRFSS. Puerto Rico, New York, New Jersey and US data are for 2013; USVI data, for 2010.

The percent of adults who receive routine care is lower in USVI compared to Puerto Rico, New York, and New Jersey. A higher percent of adults receives routine care in Puerto Rico compared to other Region II jurisdictions.

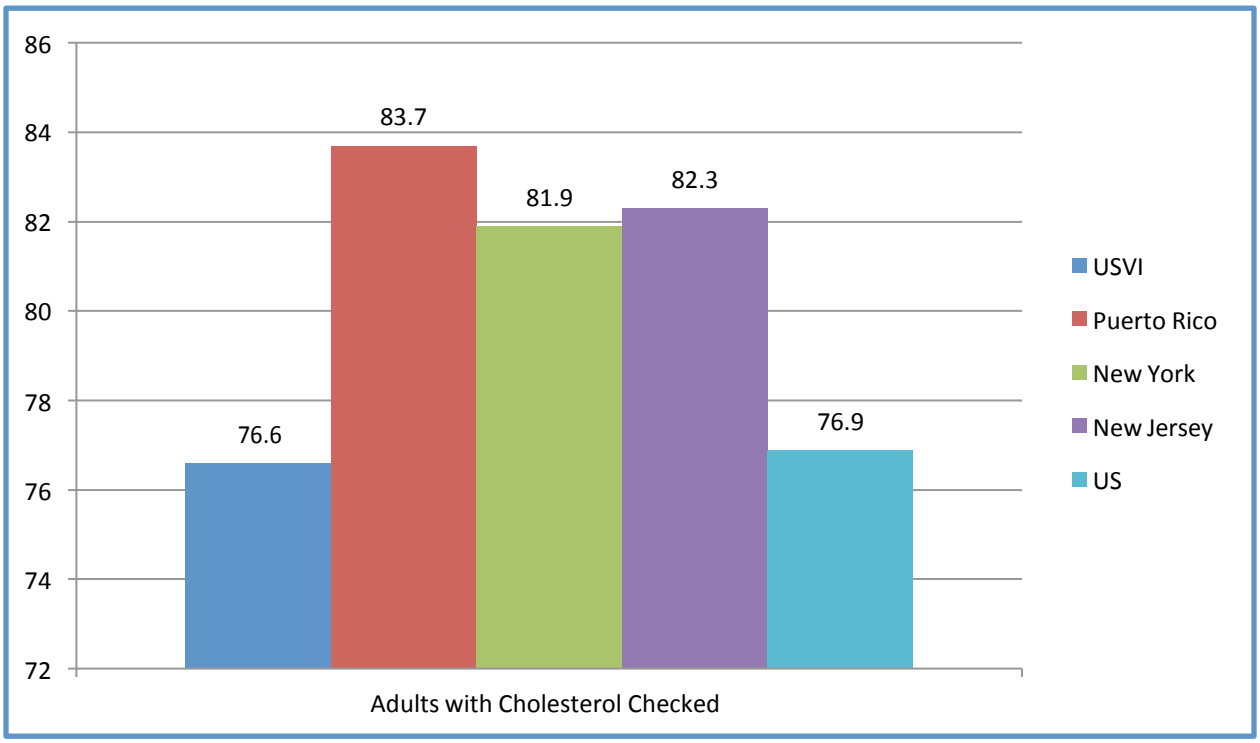
Figure 5, Percent Adults who had a Routine Dental Visit during past 12 Months



Source: BRFSS 2010

Regular use of the oral healthcare delivery system leads to better oral health by providing an opportunity for clinical preventive services and early detection or oral diseases. Nearly 58% of adults in USVI had a routine dental visit during the past 12 months, which is lower than the percentage in other Region II areas.

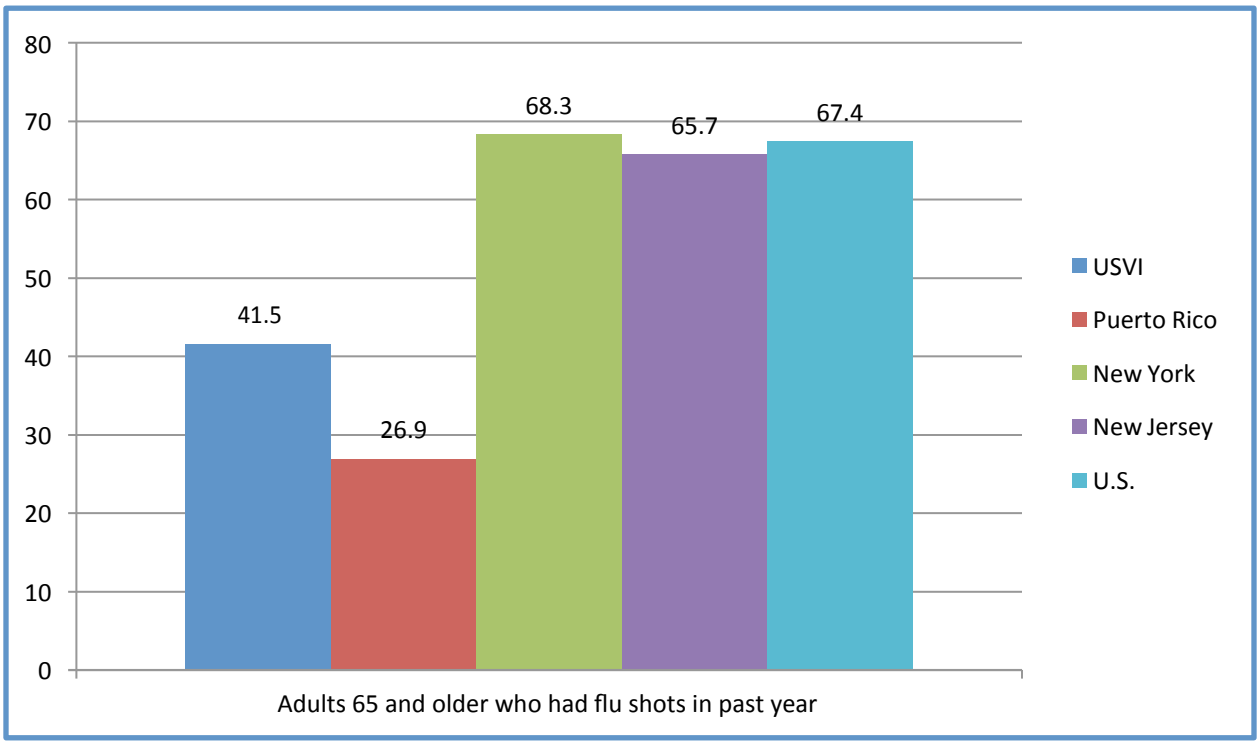
Figure 6, Percent Adults with Cholesterol Checked



Source: BRFSS 2009

The National Cholesterol Education Program recommends cholesterol screening every five years for adults 20 years of age and older. The percent of USVI adults with cholesterol screening is comparable to the percent of adults in the United States, but lower than the percent of adults in Puerto Rico, New York and New Jersey with cholesterol screening.

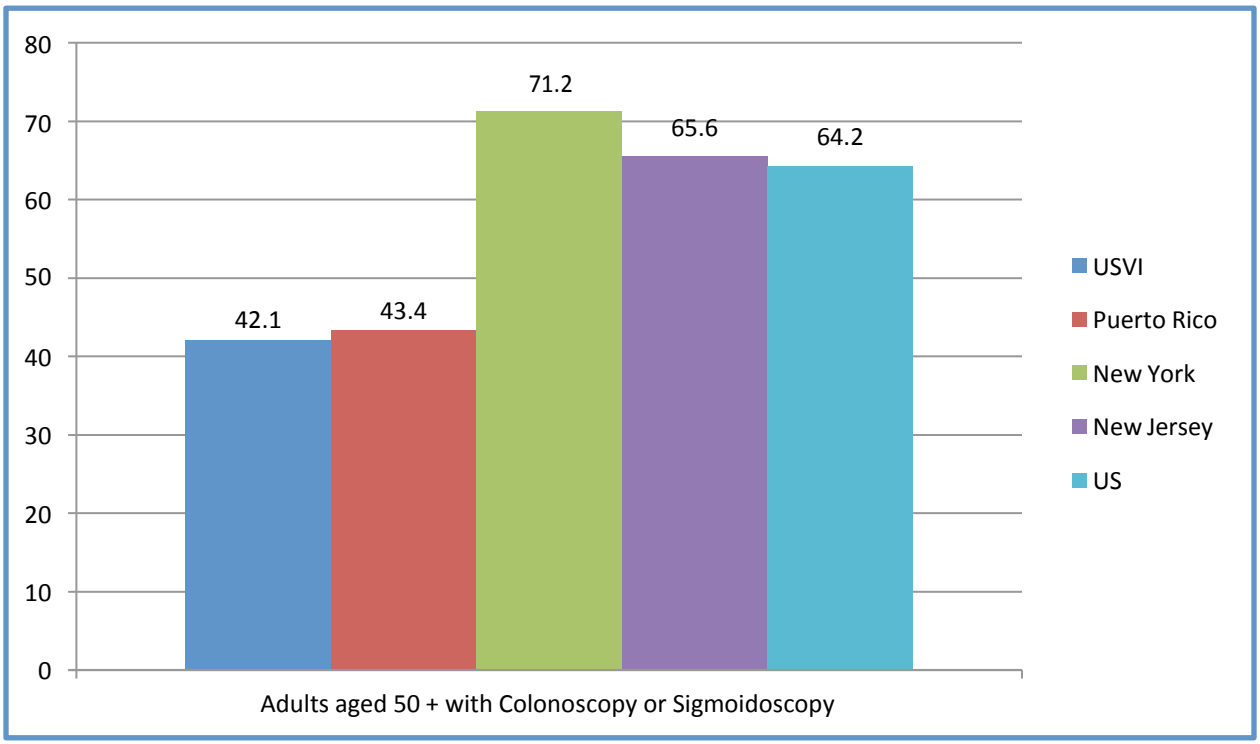
Figure 7, Percent Adults Aged 65 and Older with Flu Shots



Source: BRFSS 2010

Influenza is a serious disease that can lead to hospitalization and sometimes even death. Most flu-related deaths occur in adults 65 years of age and older[x]. Less than 50% of adults in this age group in USVI and Puerto Rico have flu shots, which is much lower than the percent of adults 65 years of age and older with flu shots in New York, New Jersey and the United States.

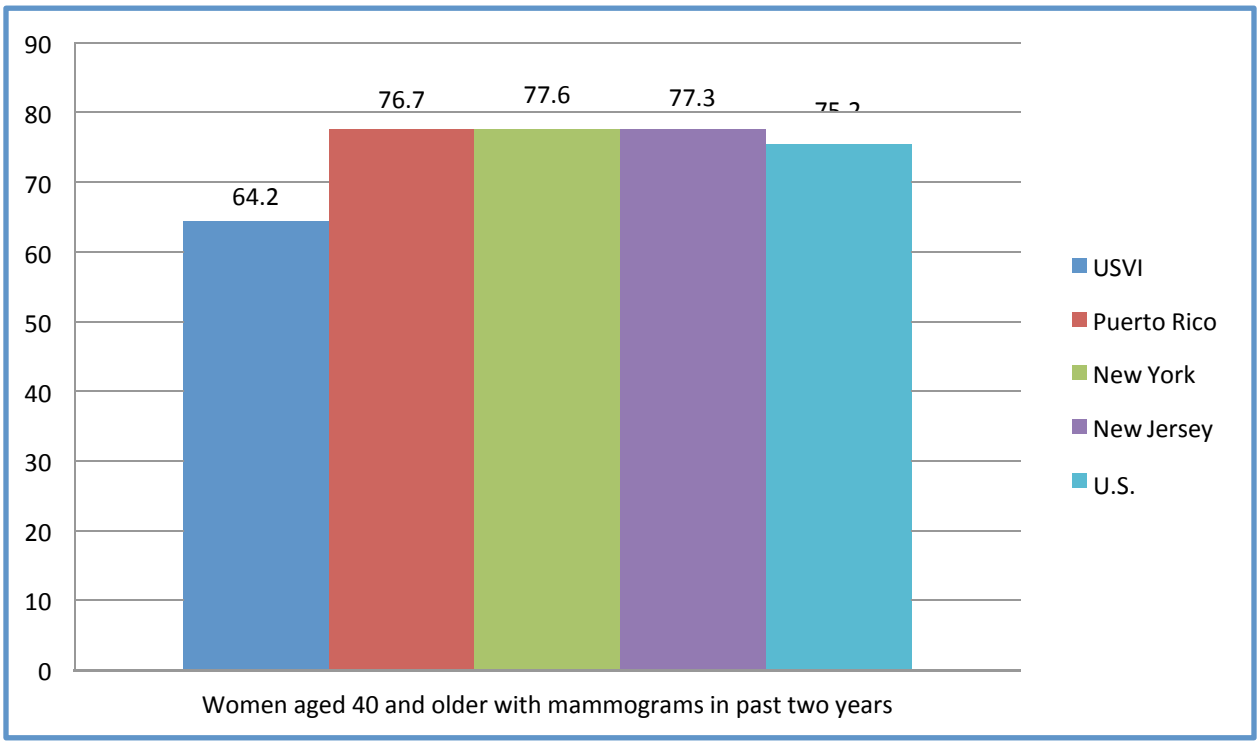
Figure 16, Percent Adults Aged 50 and Older with Colorectal Cancer Screening



Source: BRFSS 2010

The U.S. Preventive Services Task Force recommends regular screening, beginning at 50 years of age, as the key to preventing colorectal cancer[xi]. Compared to the percent of adults 50 years of age and older with colorectal cancer screening in USVI and Puerto Rico versus those in New York and New Jersey, USVI and Puerto Rico have a lower prevalence of colorectal cancer screening.

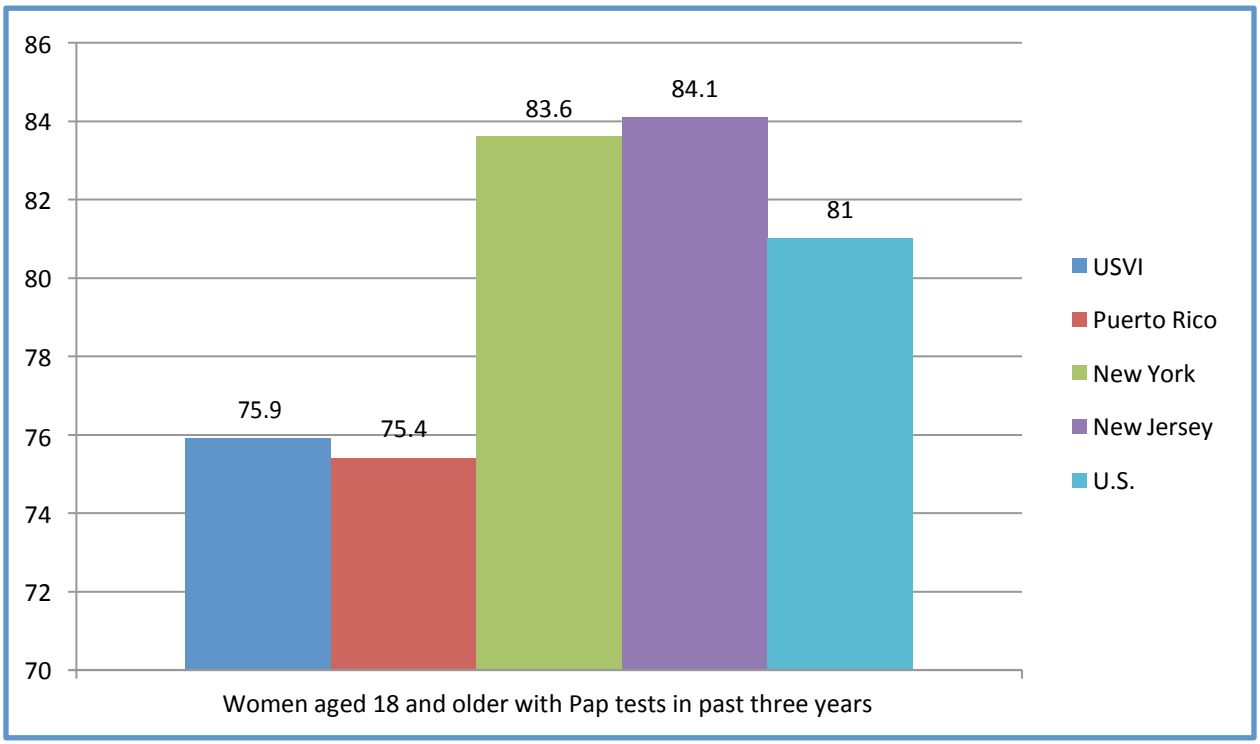
Figure 8, Percent Women Aged 40 and Older with Mammograms



Source: BRFSS 2010

Other than skin cancer, breast cancer is the most common cancer among women in the United States. The U.S. Preventive Services Task Force recommends mammography screening every two years[xii] for average-risk women 50-74 years of age. "Average-risk" women are those who are asymptomatic at 40 years of age and older; do not have preexisting breast cancer or a previously diagnosed high-risk breast lesion; and are not at high risk for breast cancer due to a known underlying genetic mutation (such as a *BRCA1* or *BRCA2* gene mutation or other familial breast cancer syndrome) or a history of chest radiation at a young age. Average-risk women 40-49 years of age should consult with their physician about when to start and how often to present for mammography screening. Compared to other Region II jurisdictions, the percent of women 40 years of age and older who have had a mammogram in USVI is much lower.

Figure 9, Percent Women Aged 50 and Older with Pap Tests

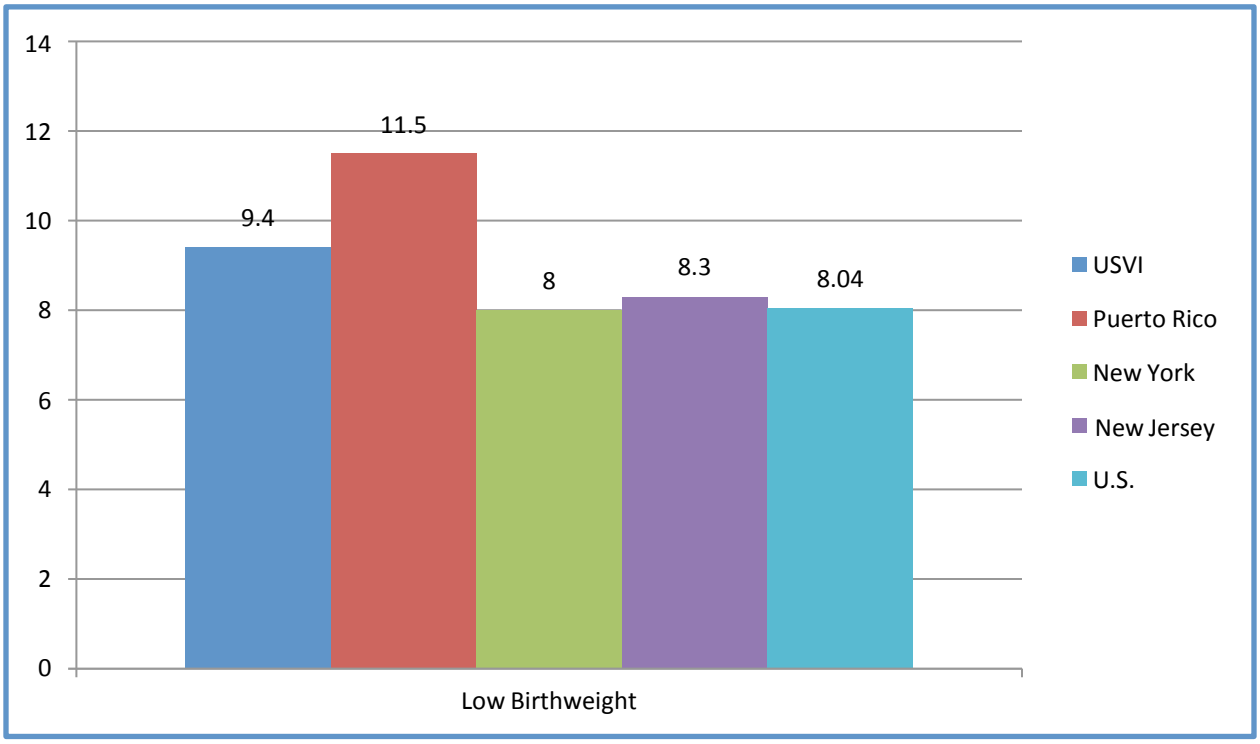


Source: BRFSS 2009

Cervical cancer is the easiest gynecologic cancer to prevent with regular screening tests and follow-up[xiii]. The Pap test screens for cervical cancer and is one of the most reliable and effective cancer screening tests available. In USVI and Puerto Rico, approximately 45% of women 50 years of age and older have had a pap test. Recent data show that approximately 80% of women have had a pap test in New York, New Jersey and the United States.

Health Outcomes – Morbidity

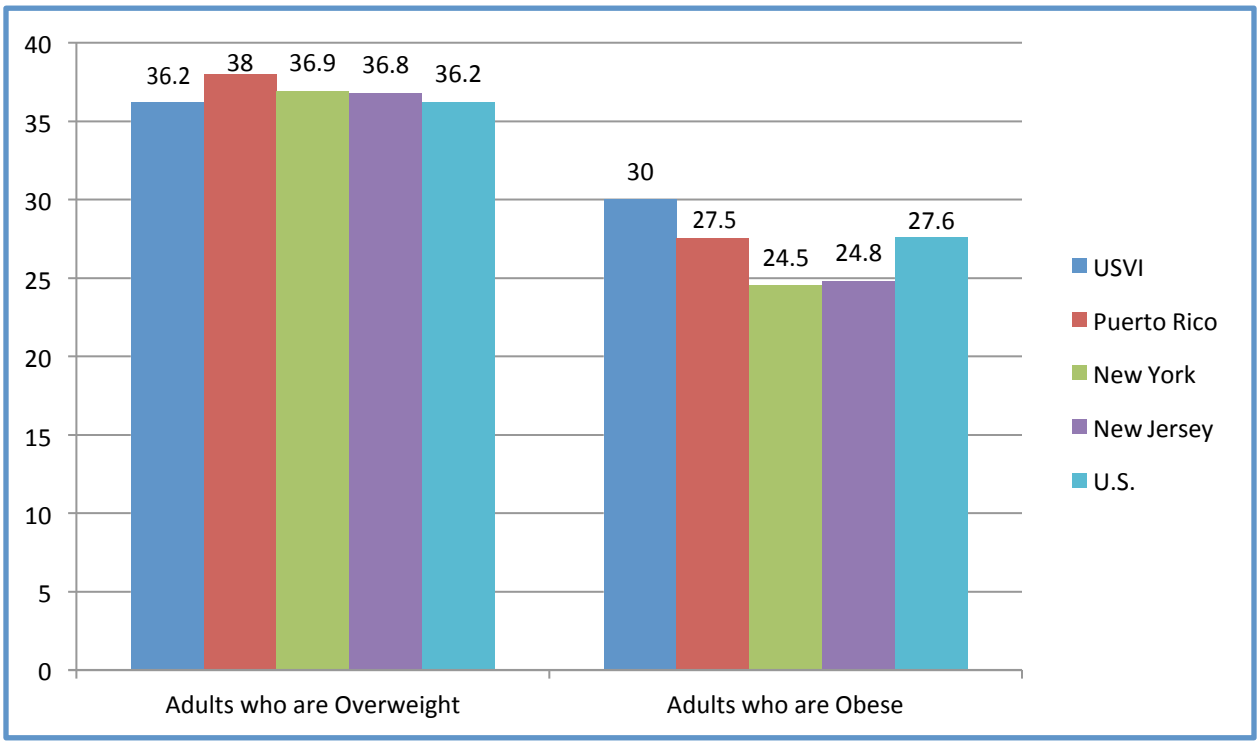
Figure 10, Percent Low Birthweight Newborns [birthweight less than 2500 grams]



Source: National Vital Statistics System 2014

Low birth weight can increase an infant's risk of death in the first few days of life and also can increase the likelihood of developmental problems later in life[xiv]. "Low birth weight" is defined as infants who weigh less than 2,500 grams (approximately 5 lbs., 8 oz.) at live birth. This measure is included in the list of objectives for Healthy People 2020 as an effort to reduce the national rate of low birth weight to a target of 7.8 %. The percent of reported low birth weight newborns across all parts of Region II is higher than the national goal of 7.8 %. However, the higher rates in Puerto Rico and USVI, compared to New York, New Jersey and the nation, suggest another area of unmet need.

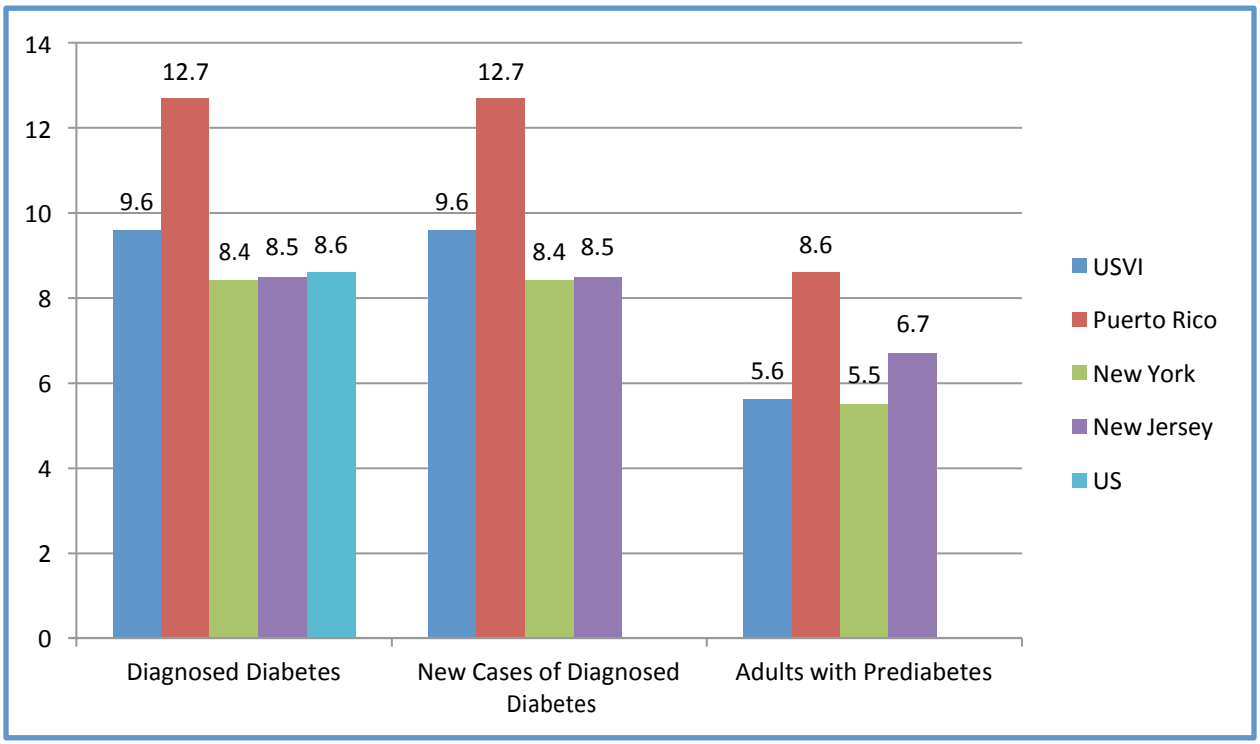
Figure 20, Percent Adults Overweight or Obese



Source: BRFSS 2010

"Overweight" and "obesity" are defined as the body mass index (BMI) and are calculated based on an individual's weight and height. Overweight is a BMI range of 25.0 to 29.9, while obesity is a BMI range of 30.0 and above. More than one-third of the populations in Region II and the entire country meet the BMI range for overweight[xv]. Compared to New York and New Jersey, the percentage of obese adults in USVI and Puerto Rico is greater.

Figure 11, Diabetes --- Age---Adjusted Diagnosis Rate per 100,000 Population

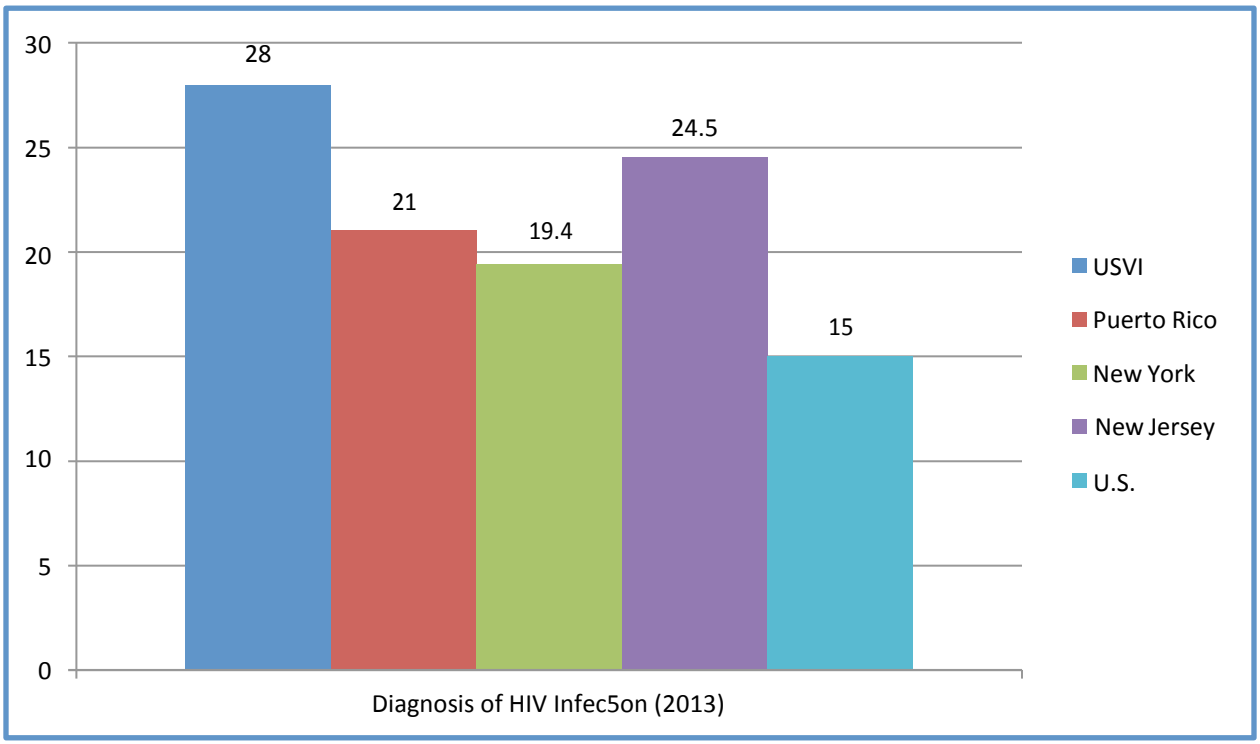


Source: [National Diabetes Surveillance System 2010]

The Centers for Disease Control and Prevention (CDC) recommends a diabetes/glucose intolerance test for adults 45 years of age and older [xvi]. Screening is particularly important for persons with certain genetic risk factors for type 2 diabetes, such as specific ethnic origins (e.g., African Americans, American Indians, Asian Americans, Pacific Islanders, and Hispanic Americans/Latinos) or those who engage in unhealthy lifestyles (e.g., physical inactivity, smoking, unhealthy diet, overweight or obese). Surveillance of diabetes prevalence and incidence rates is critical in preventing the disease, controlling its significant complications, and managing its estimated direct and indirect costs of $245 billion per year[xvii]. The rising incidence of type 2 diabetes among children and adolescents (primarily due to inactivity, screen time, unhealthy diets and obesity) will significantly increase these estimated costs.

Puerto Rico and USVI have the top two highest age-adjusted prevalence (diagnosed diabetes) and incidence (new cases of diabetes) rates of diabetes per 100,000 population in Region II. Puerto Rico and New Jersey account for the top two highest rates of adults with pre-diabetes in Region II. Close monitoring of persons with pre-diabetes and early interventions with diet and exercise are essential in changing the course of the disease and preventing the development of diabetes.

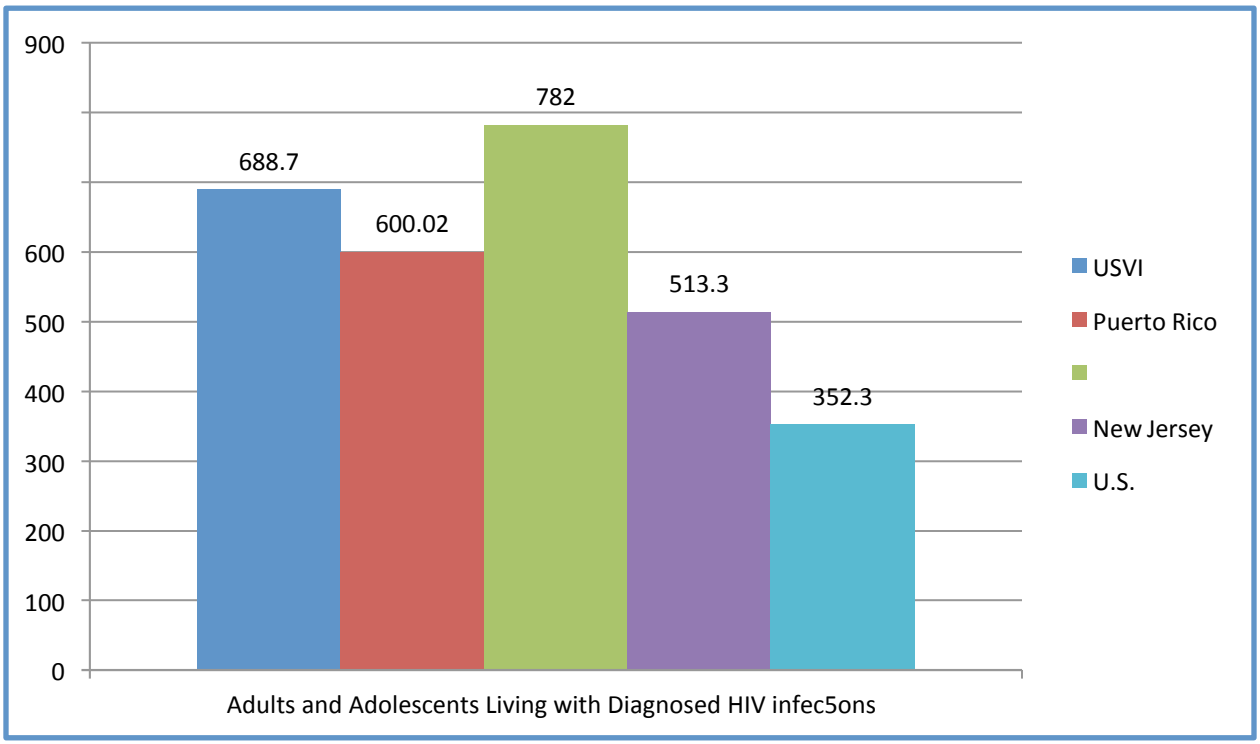
Figure 12, HIV/AIDS --- Diagnosis Rate per 100,000 Population



Source: **HIV Surveillance Report 2013**

This measure represents the cases of adults/adolescents diagnosed in 2013 with human immunodeficiency (HIV) infection, including living or deceased persons who have progressed to acquired immunodeficiency syndrome (AIDS). The rate is calculated based on the Region II territory, state or entire country per 100,000 population[xviii]. HIV/AIDS rates for the two Region II territories and two states are higher than the national rate overall, but the USVI and New Jersey rates are notably higher than other parts of the region. These data suggest an area that needs programmatic interventions and plans for improvement.

Figure 13, Adults and Adolescents Living with Diagnosed HIV Infection per 100,000 Population



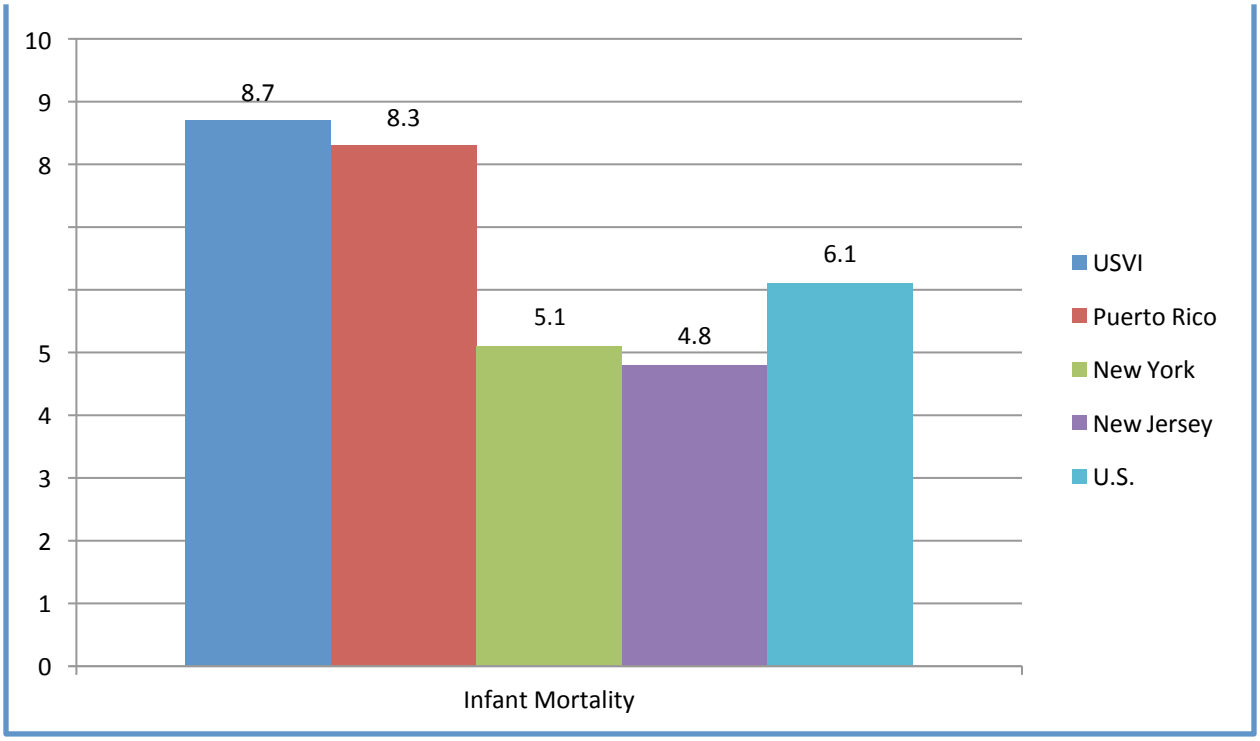
Source: **HIV Surveillance Report 2013**

The cumulative cases of adults/adolescents living with diagnosed HIV/AIDS and affected by this infection in each part of Region II and the entire country, regardless of the year of occurrence or diagnosis, are presented and expressed per 100,000 population[xix]. Rates for each part of Region II are higher than the national rate. New York and USVI have the top two highest rates of persons living with HIV/AIDS.

Health Outcomes – Mortality

Infant Mortality

Figure 14, Infant Deaths per 1,000 Live Births

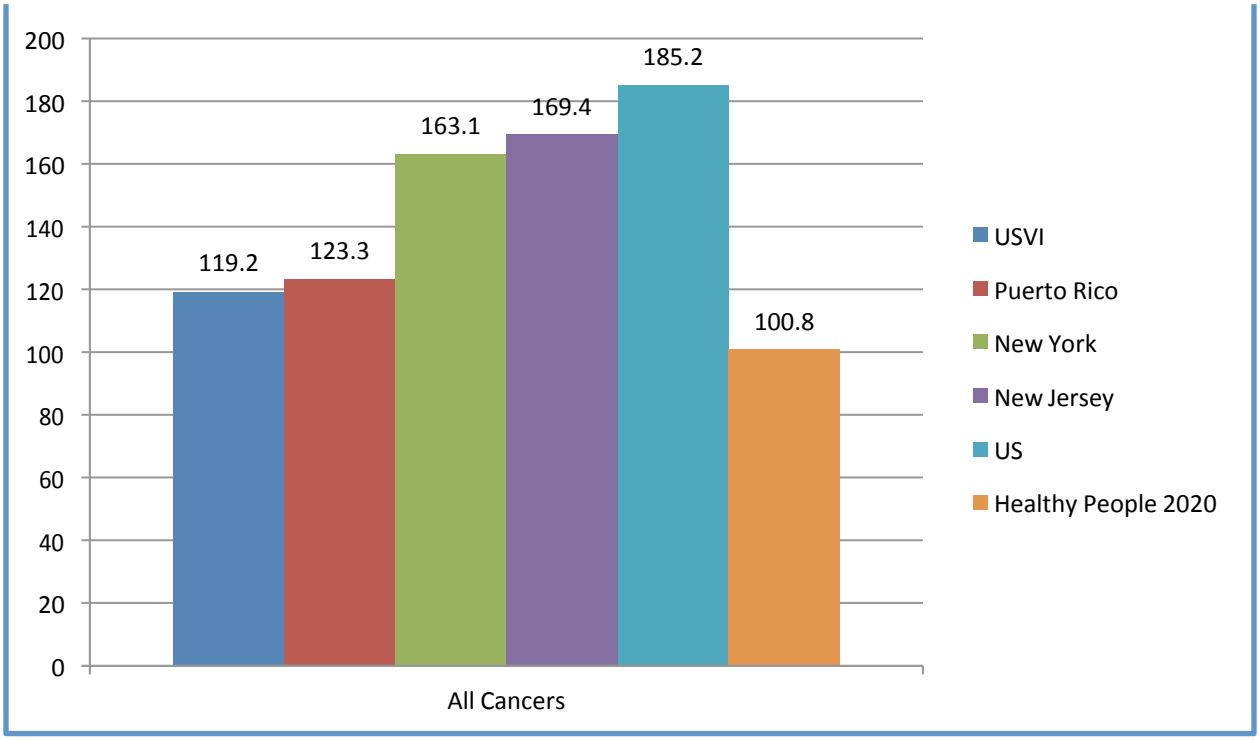


Source: [National Vital Statistics System 2014]

"Infant death" is defined as a death of a live-born infant within the first year of life[xx]. Infant death includes neonatal death (a death occurring under 28 days of age in a given year) and post-neonatal death (a death occurring from 28 days to one year of age in a given year[xxi]). The rate for infant deaths is calculated based on the total number of live births in each part of Region II and for the entire country and is expressed per 1000 live births[xxii]. Healthy People 2020 includes objectives to reduce the rate of fetal and infant deaths, with a target rate of 6.0 infant deaths per 1,000 live births. Infant mortality rates in USVI and Puerto Rico are higher than those in New Jersey and New York, the national rate, or the Healthy People 2020 target goal. However, these data do not reflect breakdowns of infant mortality by race/ethnicity. Caution should be taken in the use of these data because the literature documents that infant mortality is notably lower among whites; significantly higher among blacks/African Americans (3-4 times higher than whites); and slightly higher among Hispanics than whites and close to the total infant mortality rate. Rates for subpopulations should be documented to plan and target interventions to address infant mortality.

Select Leading Causes of Death

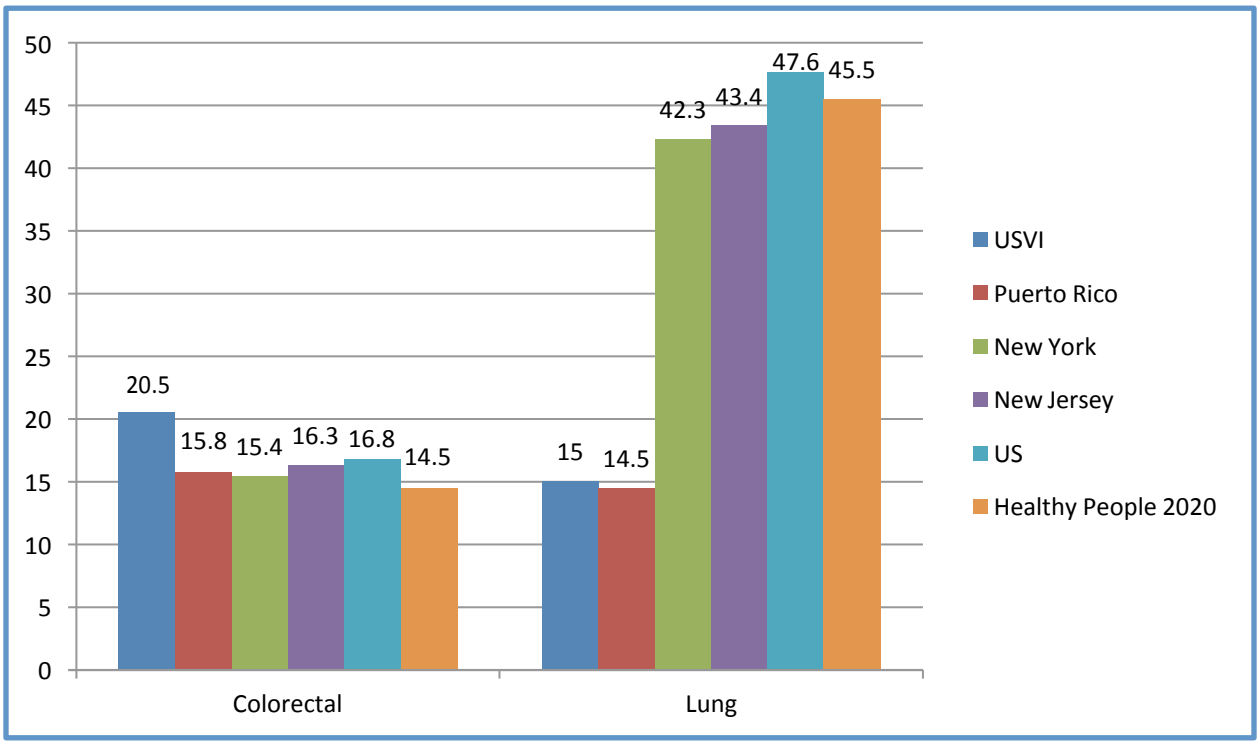
Figure 15, Cancer Mortality rates (deaths with malignant neoplasm of all body sites combined as the underlying cause of death) for 2010 and Healthy People 2020 Target Rates



Source: HHS Office of Women's Health, Health Disparities Profile 2014 - data for 2010; U.S. data from National Vital Statistics System, data for 2009-2013

This measure represents deaths with malignant neoplasm of all body sites combined as the underlying cause of death among residents of all parts of Region II and the nation overall, and are age-adjusted and expressed per 100,000 population. The all-cancers mortality rates for Region II are considerably higher than the national rate and the target rate of Healthy People 2020. USVI has the highest cancer mortality rate in the region, followed by New Jersey and New York. Additional breakdowns by site, gender and race/ethnicity may highlight areas of need in Region II for targeted resource allocation and program development to improve access of residents to early detection and treatment services, and ultimately reduce cancer mortality.

Figure 16, Colorectal and Lung Cancer Deaths per 100,000 Population

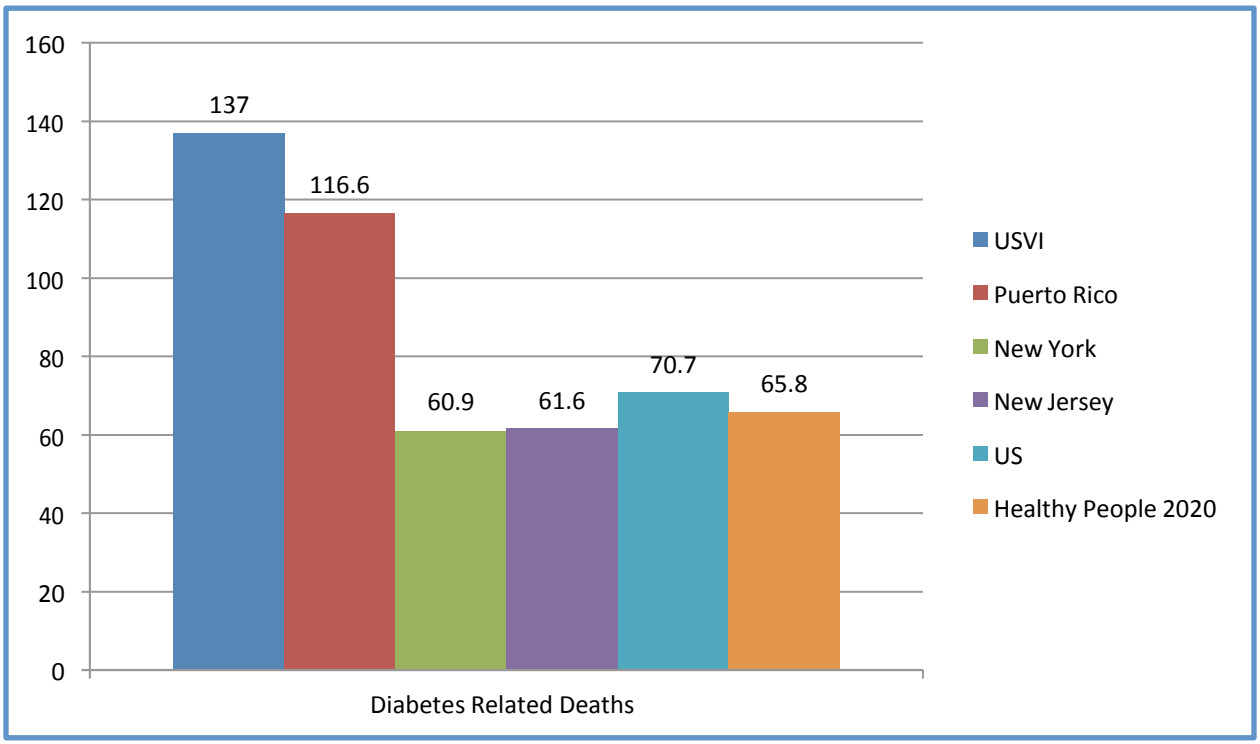


Source: HHS Office of Women's Health, Health Disparities Profile 2014 - data for 2010, U.S. data from National Vital Statistics System, data for 2009-2013

According to the Centers for Disease Control and Prevention, lung and colorectal cancers are the first and second leading causes of cancer death and among the most common cancers for both men and women in the United States[xxiii]. Risks for both cancers can be considerably reduced by use of preventable measures. The American Lung Association reports that more than 87% of lung cancer cases are caused by smoking. Efforts to help quit smoking or avoid second-hand smoke, as well as monitor and reduce radon gas in homes can be instrumental in lung cancer control. Routine screening for early detection and treatment of colorectal cancer are also effective measures to save lives. While screening rates have increased in the United States, not enough people are getting screened for colorectal cancer. In 2014, 65.7% of U.S. adults were up-to-date with colorectal cancer screening; 7% had been screened, but were not up-to-date; and 27.3% had never been screened.

Colorectal cancer deaths per 1,000 population Region II is highest in USVI compared to other parts of the region, the national rate, and the Healthy People 2020 target rate. These data suggest a need to facilitate and promote more use of colorectal screening in the area (see figure 25). Lung cancer death rates in both USVI and Puerto Rico are lower than in New York, New Jersey, the United States and the Healthy People 2020 target rate. A more in-depth analysis is warranted to determine if the data accurately reflect the situation.

Figure 17, Diabetes Related Deaths per 100,000 Population

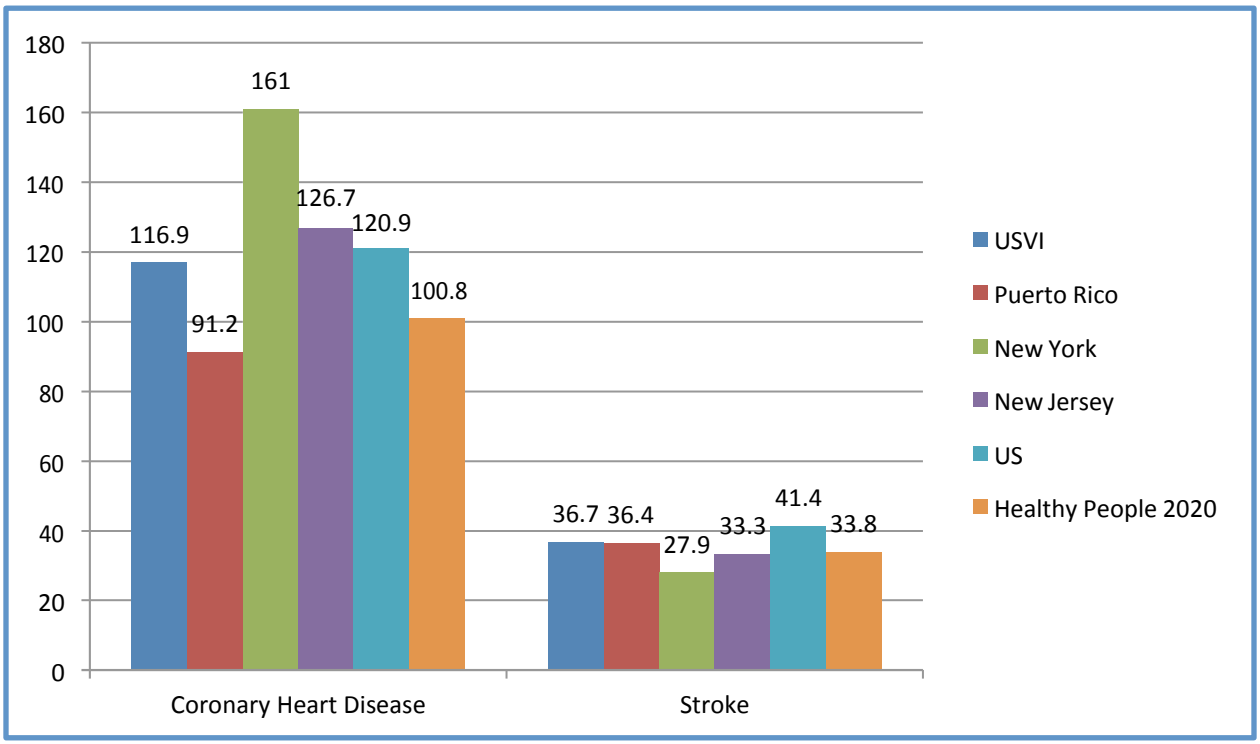


Source: HHS Office of Women's Health, Health Disparities Profile 2014 - data for 2010; U.S. data from National Vital Statistics System, data for 2010

According to the Centers for Disease Control and Prevention, diabetes was the seventh leading cause of death in the United States in 2010 based on 69,071 death certificates in which diabetes was listed as the underlying cause of death. Diabetes may be underreported as a cause of death. Several studies have found that only approximately 35% to 40% of persons with diabetes who died had diabetes listed on the death certificate and approximately 10% to 15% had the disease listed as the underlying cause of death[xxiv]. In 2003–2006, after adjusting for population age differences, the rates of death from all causes were approximately 1.5 times higher among adults 18 years of age and older with diagnosed diabetes than among adults without diagnosed diabetes.

The rates for diabetes-related deaths per 100,000 population for all areas of Region II and the United States are higher than the Healthy People 2020 target rate. USVI and Puerto Rico have the highest diabetes related death rates in Region II, with the USVI rate nearly double the U.S. rate.

Figure 18, Coronary Heart Disease and Stroke Related Deaths per 100,000 Population



Source: HHS Office of Women's Health, Health Disparities Profile 2014 - data for 2010, U.S. data from National Vital Statistics System, data for 2009-2013

Each year, the American Heart Association (AHA), in conjunction with the Centers for Disease Control and Prevention, the National Institutes of Health, and other government agencies, collects the most recent statistics related to heart disease, stroke, and other cardiovascular and metabolic diseases and publishes the data in its *Heart Disease and Stroke Statistical Update*. The latest update was released in 2016 and reported that the overall death rates attributed to cardiovascular disease (CVD) declined by 28% from 2003 to 2013[xxv]. In 2013, however, CVD still accounted for 30.8% of all deaths (or approximately 1 of every 3 deaths) in the United States[xxvi]. Based on 2013 death rate data, approximately 2,200 Americans die of CVD each day (or an average of 1 death every 40 seconds[xxvii]). The rate of deaths due to CVD is higher for males and African Americans.

The rate of coronary heart disease and stroke-related deaths per 100,000 population in Region II was highest in New York, is higher than the U.S. rate and the Healthy People 2020 target rate. The New Jersey rate is slightly higher and the USVI rate is slightly lower than the U.S. rate. Puerto Rico rate is relatively low and even lower than the Healthy People 2020 target rate. The rates of stroke for all parts of Region II are below the U.S. rate and close to Healthy People 2020 target rate.

WHAT ARE KEY SOURCES OF USVI HEALTH DATA?

The following are key datasets and data sources that report USVI health data.

BRFSS

The Behavioral Risk Factor Surveillance System (BRFSS) is the nation's premier system of health-related telephone surveys that collect state data on U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. Established in 1984 with 15 states, BRFSS now collects data in all 50 states, the District of Columbia and three U.S. territories, including Puerto Rico and USVI. USVI participated in the survey from 2001-2010. However, the territory did not gather BRFSS data from 2011-2015. The data are published at http://www.cdc.gov/brfss/index.html.

YRBSS

The Youth Risk Behavioral Surveillance System (YRBSS) monitors health-risk behaviors that contribute to the leading causes of death and disability among youth and young adults, including tobacco and alcohol use, unintentional injuries and violence, sexual behaviors, dietary behaviors and physical activities. USVI collected YRBSS data in 2006-2007. The survey data are published at http://www.uvi.edu/research/eastern-caribbean-center/documents.aspx.

HHS Office on Women's Health (OWH)

The 2014 edition of the *Women's Health and Mortality Chartbook* is a statistical resource on women's health for all 50 states and U.S. territories. The Chartbook features 28 different health indicators and highlight a number of key issues related to women's health that are being measured regularly at the state level. OWH also publishes an annual health disparities profile. The data are published at http://www.healthstatus2020.com/owh/chartbook/ChartBook Data_search.asp.

CDC National Notifiable Diseases Surveillance System (NNDSS)

NNDSS is a nationwide collaboration that enables all levels of public health (local, state, territorial, federal and international) to share health information to monitor, control and prevent the occurrence and spread of state-reportable and nationally notifiable infectious and some non-infectious diseases and conditions. NNDSS maintains and publishes official national notifiable diseases statistics from 57 state, territorial and local reporting jurisdictions in the *Morbidity and Mortality Weekly Report*. The data are published at http://www.cdc.gov/nndss/

USVI Community Survey

The Eastern Caribbean Center at the University of the Virgin Islands conducts an annual Virgin Islands Community Survey (VICS) among household residents in the territory. The survey generates official Virgin Islands statistics related to economics, population, housing, labor and employment. The last survey was completed in 2009, and the results are posted online at http://www.uvi.edu/research/eastern-caribbean-center/documents.aspx. The survey is being updated.

Virgin Islands Department of Education

Data on attendance, graduation, dropout, testing participation and assessment proficiency rates for USVI public school students are published at http://vide.nclbreports.avr247.com/vidoe/Reports/ReportsLanding.aspx.

Virgin Islands Department of Health

The *Virgin Islands Diabetes Surveillance Report*, with diabetes data from BRFSS 2001-2003, is published at http://usvidiabetes.org/sr/.

Virgin Islands Department of Labor

Data on employment, unemployment, labor force participation and wages, as well as an industry outlook are published at http://www.vidol.gov/.

Annie E. Casey Foundation/Community Foundation of the Virgin Islands

The Annie E. Casey Foundation's Kids Count Project tracks the well-being of children in the United States. Data for six topical areas – demographics, economic well-being, education, community and family, health, and safety and risk behaviors – are reported for all 50 states, Puerto Rico and USVI. The *Kids Count USVI Data Book* is published each year by the Community Foundation of the Virgin Islands. The Annie E. Casey Foundation annually produces a summary document reporting state-level data and national trends. http://www.cfvi.net/programs/kids-count.php

WHAT KEY DATASETS DO NOT INCLUDE/REPORT USVI DATA?

National Health and Nutrition Examination Survey (NHANES)

NHANES is designed to assess the health and nutritional status of adults and children in the United States. The unique survey combines interviews and physical examinations.

National Health Care Survey (NHCS)

NHCS examines factors that influence the use of healthcare resources and the quality of health care, including safety, and disparities in healthcare services provided to subpopulations in the United States.

National Health Interview Survey (NHIS)

NHIS is the principal source of information on the health of the civilian, non-institutionalized U.S. population and is one of the major data collection programs of the CDC National Center for Health Statistics. NHIS data are widely used throughout the U.S. Department of Health and Human Services to monitor trends in illness and disability and to track progress toward achieving national health objectives. The data also are used by the public health research community for epidemiologic and policy analysis of timely issues, such as characterizing populations with various health problems, determining barriers to accessing and utilizing appropriate health care, and evaluating federal health programs.

Pregnancy Risk Assessment System (PRAMS)

PRAMS provides data that are not available from other sources about pregnancy and the first few months after birth. These data can be used to identify groups of women and infants at high risk for health problems, monitor changes in health status, and measure progress toward achieving goals related to improving the health of mothers and infants.

U.S. Cancer Statistics

The *U.S. Cancer Statistics: 1999-2011 Incidence and Mortality Report* combines cancer registry data from the National Program on Cancer Registries and the Surveillance, Epidemiology and End Results Program to produce a new set of official federal statistics on cancer incidence for a single year.

WHAT ARE THE GAPS/CHALLENGES IN THE USVI DATA INFRASTRUCTURE?

CENTRAL DATA REPOSITORIES

- There are no central data repositories or annual reports relative to public health for the USVI.
- There are no central cancer or diabetes registries for the USVI, and no consistent vital statistics reports.

FEDERAL HEALTH DATA SEARCH ENGINES

Many online federal health data search engines, such as www.wonder.CDC.gov, www.healthindicators.gov, www.healthdata.gov, and www.dataCDC.gov, report minimal or no data for the USVI population. For example, the Health Indicators Warehouse currently reports nearly 1,200 health indicators derived from more than 170 different data sources, including those used to track measures for Healthy People 2020. CDC Wonder allows users to query more than 30 public-use datasets about mortality, cancer incidence, hospital discharges, AIDS, behavioral risk factors, diabetes, and many other topics. These sites do not report any USVI data.

PUBLIC HEALTH SYSTEM IN THE US VIRGIN ISLANDS

- The public health system in the USVI is still fragile. The DOH remains severely understaffed and underfunded, primarily in the areas of community health clinic services and its regulatory units. The DOH has not recently led the charge for coordinated comprehensive health services.[4]
- The DOH and other government agencies collaborate with the School of Nursing, whose faculty, staff and students are actively involved in education, environmental, health and economic research. However, limited human and fiscal resources present challenges to collaborations for research purposes.
- USVI, similar to the other territories and Puerto Rico, do not participate in key provisions of the Affordable Care Act, such as allowing access to premium subsidies to purchase health insurance on the exchange.

[4] Governor Kenneth E. Mapp, State of the Territory Address, January 26, 2015.

CALL TO ACTION

- There is an urgent need to develop a comprehensive health data system for USVI. The health data system needs to focus on both morbidity and mortality data. Systematic data collection and reporting policies need to be established. DOH's leadership role should be to monitor compliance.
- The identification of funding to support the development of a comprehensive, redundant central health data system is critical to improving the data infrastructure.
- USVI should participate in federally supported data collection and reporting mechanisms, including the YBRSS, BRFSS, and U.S. Cancer Statistics.
- The establishment of a diabetes registry is a priority since diabetes is the fourth leading cause of death in USVI.
- Federal data search sites, such as the Health Indicators Warehouse and CDC Wonder, should report currently available health data for USVI and Puerto Rico. Whenever data are available, these sites should include information in a manner similar to that for mainland U.S. populations. Although data for USVI and Puerto Rico are limited, access can still improve understanding of the health status and determinants of the territories, and facilitate the prioritization of interventions.
- Federal agencies should partner with entities within USVI to address one or more of the identified data needs. For example, OMH could continue to support interns to work with the Caribbean Exploratory Research Center and the DOH on issues that impact capacity to effectively address and reduce health disparities in USVI.
- Section 4302 of the Affordable Care Act contains provisions to strengthen federal data collection efforts by requiring all national data collection efforts to gather information on race/ethnicity, gender, primary language and disability status. While the law does not contain any specific provisions related to the US territories, OMH and federal agencies should explore opportunities to collect additional demographic data to improve understanding of health disparities in USVI.
- Long-term projects of USVI include developing an information infrastructure and strengthening data capacity. To achieve these goals, plans should be established and resources should be committed. HHS agencies that collect and report health data (e.g., CDC, CMS and HRSA) should be asked to outline strategies in their work plans on integrating USVI and Puerto Rico into their health data initiatives.

APPENDICES

A. Emerging Health Professionals
B. Project Summaries

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