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# “Bringing Testing to the People”: A Discussion of an HIV-Testing Outreach Project Targeting Impoverished Women

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## 1. Introduction

### 1.1 Health disparities related to HIV

HIV-related health disparities are differences in the incidence, prevalence, mortality, and/or burden of HIV and related adverse health conditions that exist among specific population groups. Health disparities exist within the impoverished or low-income housed population in Puerto Rico with respect to HIV. Formative research findings with women who live in public housing revealed a three percent self-reported HIV positive serostatus (Norman, et. al., 2008). However, due to the stigma associated with HIV in Puerto Rico, especially within the residents of public housing, this figure is likely to be an underestimation of the real seroprevalence (Norman, et. al., 2009). The vast majority is unemployed (95%) and has no visible means of monetary support. As such, they qualify for “Reform, as the local Puerto Rico Health Reform program (*Reforma de Salud de Puerto Rico* in Spanish), is called. This is a government-run program which provides medical and healthcare services to indigent and impoverished citizens of Puerto Rico. It is run by means of contracting services of private health insurance companies, as opposed to the traditional system of government-owned hospitals and emergency centers. The Reform is administered by the Puerto Rico Health Insurance Administration and, as of December 31, 2005, provides healthcare coverage to over 1.5 million Puerto Ricans, which equals to 37.5% of the island population (PR Department of Health, 2010). While these persons qualify for Reform, many of them have no means of accessing needed health care due to the costs of or lack of transportation.

The course of HIV disease varies among individuals, with complications such as opportunistic infections (OIs) emerging at different times throughout the trajectory of the illness. The goal of healthcare is to keep the individual as healthy as possible through health-promoting behaviors. When examining the quality of life among PR residents, one study found that older women, persons with less education or *lower income*, persons unable

to work, and those who were overweight or who had diabetes or high blood pressure reported more days for which they were physically or mentally unhealthy during the 30 days preceding the survey (CDC, 2002). Health-promoting behaviors include good nutrition and ongoing risk reduction, as well as making persons aware of their HIV status. Ensuring that people know their HIV status and receive adequate care if infected can improve clinical outcomes and reduce the transmission of HIV. However, researchers estimate that 21 percent of persons infected with HIV are unaware that they have the disease (IOM 2011). Once persons are made aware of their positive status, they can be offered treatment and appropriate care, which can help decrease HIV-related disparities associated with morbidity and mortality.

### **1.2 Why impoverished females in Puerto Rico are considered disproportionately affected by HIV/AIDS**

As of September 2011, 43,648 cases of AIDS have been reported in the island (PR Department of Health, 2011). Women constitute 20% of the total number of prevalent cases. Heterosexual transmission accounts for 61% of the cases among women, followed by injecting drug use (IDU) (PR Department of Health, 2011).

Puerto Rico has one of the highest incidence rates of AIDS in the Americas (CDC, 2010). In the year 2009, rates of HIV diagnoses among female adults and adolescents ages 13 years and older in Puerto Rico had then 5<sup>th</sup> highest rates among 40 states and five US territories, with a rate of 15.4 cases per 100,000 population (CDC, 2010). Prevalence rates of adult and adolescent females living with a diagnosis of HIV infection, year-end 2008, revealed that Puerto Rico was the 3<sup>rd</sup> highest, with 349.7 cases per 100,000 population. Lastly, in terms of rates of AIDS diagnosis among adult and adolescent females in 2009, Puerto Rico reported the 5<sup>th</sup> highest rate with 13.2 cases per 100,000 population being reported.

The estimated HIV prevalence was calculated for women and girls living in Puerto Rico using the data described above and the population of Puerto Rico residents, which includes approximately 3.8 million, of which approximately 1.6 million are female aged 13 years and older (US Census Bureau, 2011). At the end of 2008, the estimated prevalence among women and girls ages 13 years and older living in Puerto Rico was 69 cases per 10,000 women (0.69 per 100) (CDC, 2010). While this prevalence rate may seem to be low, self-reported data collected from 1,138 women during the formative phase of *Proyecto MUCHAS* revealed a rate more than four times that estimate, with three percent self-reporting their HIV status as positive (Norman, et. al., 2008). This rate does not include those women who refused to disclose their status on the survey. If we include assume they are positive and include them, the rate goes up to 3.9 per 100. As the percentage of AIDS cases among women continues to increase in Puerto Rico, it becomes imperative that research and prevention efforts target additional groups of women who may be at increased risk of HIV.

### **1.3 Social and cultural factors that exacerbate HIV risk for impoverished women**

HIV risks are exacerbated for impoverished women by a number of social and cultural factors. Poverty is a major factor that contributes to the increased risk of HIV for women. Many experts believe poverty, unemployment, and a lack of education are helping to drive the growing HIV problem among women. Women living in inner-city poor neighborhoods

are often in poor health and without access to healthcare for prevention or treatment (Women’s Health, 2011). While risky behaviors in these communities directly spread HIV, urban poverty is clearly playing an important role because it is directly related to lack of or low education, poor housing conditions, and other factors associated to low self-esteem, and lack of knowledge about health issues. Previous research has examined the relationship between socioeconomic status and HIV risk and identifying significant associations between the two, such as persons who are considered low-income are more likely to be HIV positive than are their higher income peers (CDC, 2011; Johns, Bauermeister, & Zimmerman, 2010; Dinkelman, Lam & Leibbrandt, 2007). The findings from these studies suggest that impoverished persons are at increased risk for HIV infection because of the heightened risk that stems from the increased HIV prevalence within their social/sexual networks. Furthermore, the physical, psychological, and social circumstances in which their poverty places them may also increase their risk of HIV exposure.

In addition to the risk that poverty imposes on impoverished women, another social issue contributing to increased risk for women and girls has to do with gender socialization (Carovano, 1992). *Gender* refers to the widely shared expectations and norms held by a society with regard to appropriate male and female behavior, characteristics, and roles. It is a social and cultural construct that differentiates women from men and defines the ways in which women and men interact with each other (Carovano, 1992). With respect to women’s vulnerability, in many societies, there is a culture of silence surrounding sex that dictates that “good” women are expected to be ignorant about sex and passive in sexual interactions, making it difficult for women to be well informed about risk reduction or, even when informed, making it difficult for them to be proactive in negotiating safer sex with their male partners (Carovano, 1992). The women in the above mentioned study sample of Puerto Rican residents are members of just such a society. Another issue related to this culture in many societies is the belief that variety in sexual partners is essential to men’s nature as men, and that men need to seek multiple partners for sexual release; the manifestations of traditional notions of masculinity are strongly associated with a wide range of risk-taking behaviors among men that affect both men and women (Courtney, 1998).

Research with impoverished minority women suggests that these women who live in male-dominated societies are at a significant risk of HIV due to increased levels of drug use, risky sexual practices, and intimate partner violence, among other factors; in addition, there may be significant levels of interaction with members of concentrated groups (Fuller, et. al., 2005; Brown-Peterside, et. al., 2002; Kalichman, et. al., 1998; Soler, et. al., 2000) While current research findings can be used to hypothesize increased HIV risk, data on impoverished Latina women in Puerto Rico are scarce, so it is difficult to estimate either the levels of HIV risk or the factors contributing to such risk for this population. Unique cultural and social factors may exist, which contribute significantly to the exacerbation of HIV and STIs risk for impoverished Latina women living in public housing developments of Puerto Rico.

As is frequently the case in Latino societies, children born into the Puerto Rican culture find themselves subjected to attitudes, mores, and customs that promote very strong gender differences. From birth on, these differences are inherent in every aspect of sexual expression and male-female interaction (Raffaelli, 2004). The outward manifestation of the principle illustrated by these differences is called *machismo*, which is the belief that males are physically, intellectually, culturally, and sexually superior to females. Because of this

pervasive attitude, women are relegated to the role of being sexual objects with the sole aim of fulfilling men's desires and needs (Montesinos & Preciado, 2001). Furthermore, in Puerto Rico, these ideas are prevalent among members of the low-income population, who tend to agree with the more traditional values as related to gender (Pico, 1998). These factors need to be considered if one is to develop culturally appropriate, effective interventions to decrease HIV/STI risk-related behaviors among these women.

Therefore, research into HIV-prevention efforts needs to explore the mechanisms by which various social and cultural constructs increase women's vulnerability to HIV. By developing an understanding of these constructions, one can begin to develop and implement appropriate and effective strategies to improve women's situations. Given the patterns and inequalities in the roles of women and men, it is not surprising that women are at high risk for HIV transmission, especially those who live in societies that are impoverished and that support male dominance over women as well as gender inequality. Furthermore, considering these additional cultural and social factors present in Puerto Rico, impoverished women who live in a male dominated society may be at a significantly higher risk for HIV than are their peers who do not live in such a society.

#### **1.4 Importance of HIV testing**

Public HIV antibody testing started in 1985 and two years later, was expanded. This expansion included the development of voluntary counseling and testing (VCT) guidelines, due to the new treatment discovery (i.e., Retrovir [AZT, Zidovudine]), which was approved by the FDA and offered to those individuals who tested positive for HIV (Cichocki, 2010). As such, since treatment has become available, it is standard procedure to offer VCT to any person seeking HIV testing. This allows for persons testing positive for HIV to learn how to modify their behavior to reduce the risk of HIV transmission to others; as well as providing the linkage medical care and services that further reduce morbidity, mortality, and improve quality of life. Today, HIV testing is almost standard operating procedure in all of the following: urgent care clinics, inpatient services, substance abuse treatment clinics, public health clinics, community clinics, correctional health-care facilities, and primary care settings. Conventional tests such as the ELISA antibody test take up to a week to complete, which lessens the likelihood that patients return for the results. In addition to the lengthy process for awaiting results, other barriers include fear of the testing results, denial that they have been exposed to HIV, an assumption that they are HIV-negative, the ramifications of an HIV-positive result, ignorance about treatment, fear of discrimination, and perceived stigma (Galvin et al., 2000).

#### **1.5 Introduction to rapid HIV testing**

Initially, conventional tests such as the ELISA and Western Blot tests were the gold standard of HIV testing. Conventional tests still play a vital role in HIV testing but current rapid HIV testing provides a less intrusive modality for determining a person's HIV status. However, it is recommended that a positive rapid HIV test result be followed up with confirmatory testing, such as the ELISA and Western Blot as described above because it is believed that confirmatory blood testing with more sophisticated testing algorithms are more accurate. Recommendations for HIV testing in health care settings, published by the Centers for Disease Control and Prevention (CDC), have led to increased rapid HIV testing in a variety



of settings including emergency departments (Haukoos et al., 2011). In 2003, CDC introduced an initiative to reduce barriers to early diagnosis of HIV infection and increase access to treatment and prevention services entitled, “Advancing HIV Prevention: New Strategies for a Changing Epidemic” (AHP). The initiative placed an emphasis on offering routine HIV testing as part of the medical visit. It also highlighted the importance of using rapid HIV tests to facilitate access to early diagnosis in high prevalence areas (CDC, 2003; Greenwald et al., 2006). The initiative promotes four strategies: (1) make HIV testing a routine part of medical care; (2) prevent new infections by working with persons diagnosed with HIV and their partners; (3) further decrease mother-to-child HIV transmission; and, (4) implement new models for diagnosing HIV infections outside medical settings. In particular, the latter strategy funded new demonstration projects using OraQuick® to increase access to early diagnosis and referral for treatment and prevention services in high-HIV prevalence settings. It created new prospects for expanding HIV testing to identify and treat HIV-infected persons earlier in the progression of the disease than ever before.

Rapid HIV tests can provide results in as little as 10 minutes, depending on the test. Persons receiving reactive test results from the initial testing visit are left with information indicative that they are highly likely to be seropositive compared with receiving no test information at the end of the visit where a conventional HIV test specimen was collected (Greenwald et al., 2006). The five FDA-approved rapid HIV tests include OraQuick Advance Rapid HIV-1/2 Antibody Test (finger prick; venipuncture whole blood, serum, plasma; oral fluid); Reveal Rapid HIV-1 Antibody Test (serum, plasma); Uni-Gold Recombigen HIV Test (serum, plasma, venipuncture whole blood); Multispot HIV-1/HIV-2 Rapid Test (serum, plasma) (Kaiser Foundation, 2005) and Clearview 1/2 Stat-Pak and Clearview Complete HIV 1/2 (Whole blood, serum/plasma) (Pacific AIDS Education and Training Center, 2009).

Similar to conventional HIV tests, reactive rapid HIV tests require confirmation. Among all rapid HIV tests, the commonalities include the process in which the tests functions (i.e., visual interpretation, lack of instrumentation, and affixation of HIV antigens to the test strip or membrane), the periodic use of external controls (i.e., known HIV-positive and -negative specimens), the use of product information sheets that are provided to the patients, and confirmation by a more specific assay (Western Blot or immunofluorescent assay) for reactive results (Greenwald et al., 2006).

### **1.6 Participant satisfaction with rapid HIV testing**

There are tremendous advantages to using rapid HIV testing, as discussed earlier, compared to conventional HIV tests. Patient satisfaction has played an integral role to sustaining the implementation of CDC’s recommended HIV screening for patients in all health care settings. It enhances that: (1) patients with newly identified infection learn the importance of seeking immediate care; and (2) patients at high risk of infection continue to be open to appropriate retesting (Donnell-Fink et al., 2011). Thus, a number of studies have been conducted to determine patient satisfaction with rapid HIV testing in a variety of settings and programs.

One of the earliest studies was conducted by Spielberg et al. (2003). A survey of elicited testing motivators, barriers, and preferences for new strategies was administered to a sample of 460 participants at the following: a needle exchange, three sex venues for men

who have sex with men, and a sexually transmitted disease clinic. It was found that most of the participants preferred rapid testing strategies (clinic-based and home self-testing).

Two years later, Spielberg et al. (2005) did further research to show that rapid HIV testing is overwhelmingly preferred by people seeking to know their status. In a randomized study involving the selection of alternative HIV counseling and testing approaches based on the results of focus groups and interviews, a preference survey administered to clients at the three study sites in Seattle (i.e., a needle exchange program and two bathhouses frequented by MSM), found that in outreach settings, alternative HIV counseling and testing strategies help to maximize the number of clients who learn their HIV test results. Furthermore, it was found that traditional HIV testing with standard counseling was least effective at providing clients with knowledge of their HIV status. Significantly more participants chose to learn their HIV serostatus based on a variety of advantages that included offering a combination of rapid oral fluid testing with written pretest materials. This proved the best way to increase the number of persons who learn their HIV status.

Antonio-Gaddy (2006) initiated a study at 61 HIV testing sites in New York State, comparing HIV test use during the first 6 months of rapid testing in 2003 with the same time period in 2002. Surveys were administered to clients at each site during the first 30 days of rapid testing and to counselors before and after training--and after 12 weeks of using rapid tests in the field. It was found that participants preferred finger-stick blood rapid tests (96.5%) over conventional HIV testing by drawing blood intravenously primarily because of the ability to get same-day results and a dislike of needles. Additionally, counselors reported increased self-efficacy or the perceived ability to administer the rapid test, and a heightened level of comfortableness in administering rapid HIV testing.

Donnell-Fink et al. (2011) surveyed 1,616 participants in the Universal Screening for HIV Infection in the Emergency Room (USHER) randomized controlled trial on patient satisfaction. The survey questions focused on overall satisfaction with emergency department (ED) visit, time spent on primary medical problem, time spent on HIV testing, and test provider's ability to answer HIV-related questions using a four-point Likert scale, ranging from very dissatisfied to very satisfied (defined as optimal satisfaction). It was found that, overall, 1,478 (91.5%) were very satisfied. These were the factors associated with less optimal satisfaction: reactive test result, aged 60 years or older, black race, Hispanic/Latino ethnicity, and testing by ED provider instead of HIV counselor.

Collectively, the abovementioned studies show that rapid HIV testing is in sync with CDC's recommendation for routine HIV screening and contributes to an increase in routine testing in health care settings around the world. The factors associated with patient satisfaction are important.

### **1.7 Challenges of rapid HIV testing**

Essentially, rapid HIV tests are screening tests that require confirmation by Western Blot or Immunofluorescence antibody, which are more specific assays. Consequently, a reactive or positive test result is considered a preliminary positive. Though highly unlikely (2%), false-positives do occur with rapid HIV testing, at slightly higher rates than the confirmatory testing, mainly as a result of medical conditions such as Hepatitis A and B viruses (Greenwald et al., 2006).

Over the past few years, several studies have been done to examine sensitivity and specificity issues associated with rapid HIV tests. Tests that require the use of oral fluid, such as OraQuick, have been found to be most at risk of false positives. Delaney et al., (2006) compared the accuracy of the rapid test performed on whole blood and oral fluid specimens with the results of conventional HIV tests by using four separate studies, in which all participants were provided oral fluid, fingerstick or anticoagulated whole blood specimens for testing with OraQuick (on both oral fluid and whole blood). Though it was found that the OraQuick test demonstrated high sensitivity and specificity for HIV antibody with both whole blood and oral fluid specimens, OraQuick sensitivity (99.1% vs. 99.6%) and specificity (99.6% vs. 99.7%) were lower with oral fluid than with whole blood. This small amount of difference becomes important with dealing with large populations tested.

A study published in *Morbidity and Mortality Weekly Report* (CDC, 2008) was published that focused on an increase in false-positives in New York clinics using oral fluid rapid tests. There were two periods of significant increases in false-positive test results over a four year span. Several months after the first increase in false-positive test results during late 2005, oral fluid testing in clinics was suspended (3 weeks) and replaced with finger-stick whole-blood rapid testing, which produced no false-positive test results. After the second increase in November 2007, the New York City Department of Health and Mental Hygiene halted all oral fluid testing in favor of finger-stick whole blood specimens. However ultimately, the performance of oral fluid rapid tests still exceeded the Food and Drug Administration's minimum threshold of 98.0% specificity and, the authors that use of oral rapid tests makes HIV testing possible in many venues where performing phlebotomy or finger sticks is impractical for screening.

### **1.8 Impact of cultural differences on HIV rapid testing**

It is reasonable to assume that the knowledge, beliefs, and attitudes about HIV testing are similar among all cultures. Persons living with HIV are stigmatized, ostracized, stereotyped, and shunned, regardless of the culture. The attitudes toward HIV testing appear to be slightly different. The failure to use HIV testing services by significant numbers of individuals at risk for HIV can be attributed to a number of factors, both on an individual as well as a societal level. Research has shown that the reasons high-risk Americans avoid HIV testing include fear of learning they are HIV-positive, belief that they are unlikely to have been exposed to HIV, belief that they are HIV-negative, the possibility of being HIV-positive, the assumption that there is little they can do about being HIV-positive, perceived stigma, and fear (Galvin, 2000; Samet, 1997).

It appears that the aforementioned reasons are not necessarily the same for other countries. Peltzer et al. (2004) sought to determine the attitudes of HIV testing and determinants of attitudes toward persons living with HIV (PLWH) among 600 first-year university students from South India, South Africa and America--vis-à-vis a self-administered questionnaire. It was found that American students had much more positive attitudes toward HIV testing than South African and Indian students. Statistical analyses showed that attitudes toward HIV testing were correlated, for instance, with contact readiness, which refers to the degree to which a person is ready to be within close proximity of a person living with HIV (PLWHs). Positive HIV testing attitudes were positively correlated with contact readiness with PLWHs, for instance.



In the Caribbean, culture has played and continues to play a large role in HIV testing acceptance, including rapid HIV testing (Coggins, 2007). One particular aspect is that of conspiracy beliefs among African Americans and Caribbean residents alike. Many members of these populations believe that HIV/AIDS is a form of genocide against Blacks, while others feel that a cure for AIDS exists, but is being withheld from the poor. Also, a significant proportion subscribes to the beliefs that HIV/AIDS treatment professionals use people (especially minority and poor persons) as guinea pigs for the government and lastly, that AIDS is a man-made virus developed specifically targeting minority persons. These views are especially prominent within the Black community.

In sum, there are notable individual and social cultural differences in the implementation and acceptability of HIV rapid testing. Across all cultures, it is undeniable that HIV rapid testing has expanded testing opportunities in both developed and underdeveloped countries. Even as some countries continue to struggle with meager resources, feeble laboratory infrastructure, a dearth of skilled phlebotomists and technicians, and weak courier networks, HIV rapid testing is becoming more routine for high risk individuals (Scott et al., 2009).

### **1.9 New approaches in HIV rapid testing**

Over the past decade, three landmark events have impacted the landscape of HIV rapid testing: the licensing of the first HIV rapid test approved for use with finger-stick whole blood specimens (which occurred in March 2004), the CDC's HIV prevention initiative to increase opportunities for HIV testing; and, publication of the CDC recommendations for routine screening for HIV in medical care settings. During the past few years, advances in HIV testing have resulted in the development of new strategies to increase the number of persons getting tested for HIV. These advances include the integration of HIV rapid testing in emergency departments, implementation of computer-assisted HIV rapid testing, and the use of electronic media to introduce HIV rapid testing to adolescents (CDC, 2007; Merchant et al., 2011; Calderon et al., 2011). Emergency departments (EDs) have been one of the leading venues for implementing innovative strategies to increase the uptake, feasibility and cost per outcome in HIV testing (Prabhu et al., 2011; Hutchinson et al., 2011). Despite the CDC's efforts to promote opt-out HIV screening in all EDs, it remains unavailable in several states. Psychosocial, behavioral and structural supports must be added to the HIV testing process to improve the chances of getting people tested. Merchant et al. (2011) made an unsuccessful attempt to use an audio computer-delivered tailored feedback intervention to determine if there were increases in ED patient uptake of opt-in, non-targeted rapid HIV screening. Though the intervention was not found to increase uptake in HIV testing, it showed that the belief of not being at risk for HIV (37.1%) was the most common reason for declining HIV screening, and the most common reason for accepting HIV screening was the convenience of being tested in the ED (36.8%). Moreover, it was determined that uptake is greater among patients who report more HIV risk and among those whose self-perceived HIV risk increases from baseline after completion of an HIV risk assessment.

With Apple surging past Exxon in August 2011 as the world's most valuable company, it has become clear that the most rewarding innovation is now social innovation and

production that takes place on the internet. Most of what has been explored to date in HIV prevention research is limited to the use of mobile technologies as mediums for information dissemination, social marketing, or medication adherence. While there is some emerging evidence of efficacy for mobile-based HIV interventions (Swendeman & Rotheram-Borus, 2010), the new media of Web 2.0 is just beginning to be explored by HIV behavioral researchers (Bull et al., 2011; Gilliam et al., 2011). New media is defined on the AIDS.gov gateway as internet-based communication that is interactive, involving content that may be co-created and information that may be collaboratively produced on an array of digital devices. New media tools include blogs, social network sites like Facebook and Twitter, mashups, video sharing sites like Youtube, virtual worlds like Second Life, webcasts and webinars, RSS feeds and social bookmarking, wikis, podcasts, texting and mobile communication, and photo sharing sites like Flickr (see <http://aids.gov/using-new-media/tools/>). There are indications that social networking media could be an effective modality to removing barriers to HIV testing and reducing stigma. Calderon et al. (2011) compared the effectiveness of a youth-friendly HIV video with in-person counseling in conveying HIV knowledge and obtaining consent for HIV testing among adolescent patients of an urban ED using a convenience sample of 200 stable, sexually active people aged 15 to 21 years in an urban EDs. The results indicate that a youth-friendly HIV educational video improved adolescents' HIV knowledge and increased their participation in HIV testing more than in-person counseling. This finding is consistent with other research, including a recent meta-analysis showing that effect sizes on HIV risk indicators are similar to human-delivered interventions among 12 randomized controlled trials of internet or computer-based HIV risk reduction interventions (Noar, et. al., 2009; Swendeman & Rotheram-Borus, 2010).

An ongoing study funded by the National Institute of Nursing Research may be the first of its kind to investigate the efficacy of social media as a delivery portal for HIV prevention (Bull et al., 2011; Gilliam et al., 2011). Entitled the *Just/Us* study, the project involves a randomized trial of a Facebook intervention for youth of color. The visualization of HIV-related metrics using the internet has the potential to engage individuals outside the boundaries of traditional health care delivery and social services. The MIT Media Lab recently instituted a new research group, New Media Medicine, to discover and implement new approaches in this area. One innovation involves internet-delivered visualization of antiretroviral drug activity at the cellular level based on an individual's lab monitoring (Moss, 2011). This technology is designed to be an HIV medication adherence tool, shared between the patient and his provider.

Initiatives to increase uptake of HIV testing across various settings are continuing to be implemented by local, state, and the federal government. In 2007, the CDC expanded funding to 25 health departments in the *Expanded HIV Testing Initiative*, to enhance the obtainability and accessibility of HIV testing services, facilitate adoption of HIV screening in health-care settings, and increase identification of undiagnosed HIV infection in populations disproportionately affected by HIV (Vaill, et. al., 2011). This initiative has been enhanced to reflect key aspects of the new White House National HIV/AIDS HIV Prevention Strategy. Pivotal to the national strategy is to view HIV testing as the first step in what is frequently described as a treatment or engagement cascade. This cascade is a series of activities that are developed to make persons aware of their HIV status to linking them with care as well as adhering to their medication regime. They must be followed in sequential order to be effective (Gardner, et. al., 2011).

### 1.10 The role of rapid HIV testing in addressing HIV-related health disparities

The Department of Health and Human Services' Healthy People 2020 defines a health disparity as a particular type of health difference that is closely linked with social or economic disadvantage. Health disparities adversely affect groups of people who have experienced greater social or economic obstacles to health based on their racial or ethnic group, religion, socioeconomic status, gender, mental health, cognitive, sensory, or physical disability, sexual orientation, geography, or other characteristics historically linked to discrimination or exclusion. as the differences that occur by gender, race or ethnicity, education or income, disability, geographic location, or sexual orientation (U.S. Department of Health and Human Services, 2011).

In 2002, Smedley, Smith, and Nelson published a report entitled, "Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare". The purpose of the report was to examine how bias, prejudice, and stereotyping contribute to unequal health care treatment. Among numerous findings, it was determined that there two sets of factors that contributed to disparities in health care. The first set of factors includes the operation of the healthcare systems and the legal and regulatory climate, in which they operate are significant. The second set of factors is the result of a confluence of three mechanisms: (1) bias (or prejudice) against minorities; (2) greater clinical uncertainty when interacting with minority patients; and (3) beliefs (or stereotypes) held by the provider about the behavior or health of minorities.

Minority populations typically experience higher rates of morbidity and mortality for conditions such as diabetes, cardiovascular disease, some forms of cancer and HIV/AIDS (CDC, 2005). In communities of lower socioeconomic status, the residents (i.e., gay men, drug users, prisoners and formerly incarcerated persons, the homeless, and those who suffer from a variety of mental health disabilities) are further marginalized by higher rates of HIV-related morbidity and mortality (NMAC, 2006).

CDC and other federal agencies have made tremendous strides to address health disparities in the incidence of HIV/AIDS. This has been done by prioritizing several issues: 1) enhancing and improving partnerships; 2) increasing screening and testing for diseases in populations with known health disparities; 3) adopting an integrated service model to improve health care delivery; 4) improving monitoring through the enhancement of current data systems and the development of new systems; and, 5) adopting new diagnostic, treatment, and prevention technologies (Steele et al., 2007).

CDC's 2003 "Advancing HIV Prevention" initiative focused on HIV prevention by emphasizing increased HIV testing. A number of years later, the revised recommendations for HIV testing incorporated routine opt-out HIV screening guidelines for all patients ages 13-64 in medical settings, regardless of their HIV risk. This was a considerable effort to reduce barriers to testing by eliminating previous requirements to accompany each HIV test with pretest counseling and separate written informed consent (CDC, 2006).

This initiative expanded rapid HIV testing efforts considerably. There are barriers (i.e., conflicting guidelines among federal agencies, problems with insurance coverage of routine testing, low reimbursement rates for HIV testing, and lack of programs that support clinician education and training in HIV testing) that impact the expansion of HIV testing.

However, as technology advances, new strategies are being developed that will promote expanded HIV testing. Expanding programs to notify partners of HIV-positive individuals, linking HIV testing with other health care and social services, and mounting media and social network outreach efforts are all facilitators to HIV testing, as outlined by Institute of Medicine (2011). Particularly, rapid HIV tests continue to be the preferred modality of testing by participants because the results are immediate and help reduce the number of people who fail to receive their test results. Rapid testing affords the opportunity of underserved individuals, including racial/ethnic minorities) to receive HIV testing at their home or outside of a clinic setting. Increasing the HIV testing among members of this disproportionately affected population addresses one of the top 20 priorities as outlined in *Healthy People 2020* (U.S. Department of Health and Human Services, 2011). Identifying persons who are HIV-infected and unaware of their status can lead to increasing access to care and improving health outcomes for people living with HIV, which includes a decrease in HIV-related morbidity and mortality and a better quality of life in general. This, in turns, decreases HIV-related health disparities that currently exist among members of this population.

## **2. A discussion of *Proyecto MUCHAS*, an HIV-testing outreach project**

### **2.1 The inception of *Proyecto MUCHAS***

This part of the chapter will describe the development of the HIV testing outreach project targeting impoverished female residents living in public housing developments (PuHD) in Ponce, Puerto Rico (PR) entitled *Proyecto MUCHAS*. The idea for working with women unfolded in 2005, when the principal investigator (LR Norman) relocated to Ponce, PR and assumed her post at the Ponce School of Medicine and Health Sciences. In reviewing the literature of HIV preventions that had been implemented with certain sub-populations in PR, it was determined that heterosexual women, especially those impoverished, had been basically ignored. Only one study that targeted this population was found and it was conducted close to 20 years ago (Hunt, et. al., 1993). Therefore, based on previous knowledge of the increased risks that exist among members of this population documented in published research with U.S. samples, it was decided to target this population for research.

Seed money came from the Puerto Rico Comprehensive Center for HIV Disparities (PR-CCHD, NCCR Grant # U54RR19507) to conduct a two-year formative research project, which did not include HIV testing. It was started by going to the PuHD administration and getting permission and their support for research. The research team then met with the individual administrative staff at each of the PuHD we targeted during this phase (n=23 out of 25 that are managed by Machuca and Associates).

The team also decided it was important to come up with a name and a logo for the project, which would be recognizable to residents of PuHDs. The project's name became *Proyecto MUCHAS*, which stands for Proyecto - Mujeres United Combatiendo - Alerta Social. This translates into the English phrase: “Women Fighting HIV: Social Alert.” Along with it, a logo was devised so that when residents see this acronym and the logo, they know it is associated with this research project (see Figure 1 below).

In addition, the research team also developed a web-page on the school's website with the above logo and a message about the goals of the project. The web address is





Fig. 1. Proyecto MUCHAS Logo

<http://www.psm.edu/MUCHAS/index.htm>. Lastly, the project colors are pink (both light and dark) and the logo embossed onto t-shirts, which are worn by the research team housing on the days that HIV/STI testing is being conducted.

Eligibility criteria included being female and a resident of the PuHD. A non-probability sampling approach was employed for the study (which is explained in detail below). Once a PuHD was selected, posters were placed up to announce that the project would be coming to the PuHD on a certain date and that all women were invited to come to the community center and participate in the study (See Figure 2 for Illustration of Flyer).

**Mujeres Combatizando el VIH:  
Alerta Social**

**Pruebas y prevención de riesgos de contagio del VIH, impactando a los residentes del Residencial Público.**

Invitamos a todos los residentes, hombres y mujeres, a participar en esta investigación la cual se estará llevando a cabo en el Centro Comunal. Se estarán realizando pruebas gratis de VIH (oral) y enfermedades de transmisión sexual (gonorrea y clamidia) (a través de la orina). Recibirá (\$20) como compensación por su tiempo invertido, luego de completar un pequeño cuestionario. Si eres mayor de 21 años de edad, estas sexualmente activo (o has tenido relaciones sexuales en el último año) y eres residente de este Residencial Público, únete y participa.

Fecha: día, mes, año

Hora: 10:00 a.m. – 3:00 p.m.

Si necesitas información adicional por favor comunícate:  
-Dr. Lisa Norman at 812-271-9173 (ingles)  
-Ms. Lynn Cintrón at 787-298-1880 (español).

Fig. 2. Flyer Posted at PuHD to Invite Residents to Participate in *Proyecto MUCHAS*.



All eligible women were invited to participate. Data were gathered between April and August 2006 from 1138 women in 23 various PuHDs across the city of Ponce.

The research team then conducted four focus groups with 39 various members of the population at two of the large public housing developments (PuHD) (Lopez Nussa and Dr. Pila) to gather the formative data on their knowledge, perceived risks, attitudes, and behaviors related to HIV prevention. These focus groups revealed some very important information and the results were used to inform the development of a quantitative instrument. The results of the focus group have been published (Abreu, et. al., 2010). The instrument was piloted with a sample of 30 women in order to assess the ease of completing the assessment tool, to determine if the questions were easily understood, and to ensure that the instrument could be completed in a timely fashion. On the basis of the first piloting phase, revisions were made. In addition, focus groups were used to validate the instrument, with 10 female residents participating to review the quantitative assessment tool for appropriate language and content. Following the final revision, one focus group was conducted as a method to validate the survey instrument. It went over every question to make sure they were understandable and culturally appropriate. After this focus group was conducted some changes were made to the questionnaire and the version was finalized and duplicated and administered to the female residents of PuHDs. After the research team went through this time-consuming but very necessary protocol, the survey instrument was implemented to 1138 residents in the 23 PuHDs, between April and August 2006.

Women completed the assessments in the community center room within each housing development. Informed consent was received from every respondent. Because of the nature of the questions and the possible perceived threat of addressing issues related to sexual and drug-using behaviors, the instrument was self-administered with no identifiers, providing anonymity to the respondents. Research assistants provided support for those women who were unable to read the questionnaire or who needed other assistance by reading the survey to them or completing the survey on their behalf. Each woman received \$10 as compensation for completing the survey. All surveys were administered in Spanish. This survey was a baseline, formative survey, occurring before any intervention or HIV-related activities were provided for the residents.

## **2.2 Development of *Proyecto MUCHAS* testing project**

### **2.2.1 Prevalence of HIV among women living in Puerto Rico**

Using these results and the population of Puerto Rico, as presented above, along with the self-reported HIV prevalence among female residents living in PuHDs, the research team concluded that this population was disproportionately affected by HIV. As the percentage of AIDS cases among women continues to increase in Puerto Rico, it becomes imperative that research and prevention efforts target additional groups of women who may be at increased risk of HIV.

### **2.2.2 Rationale for developing and implementing HIV testing out-research project**

It was self-reported data that drew the research team's attention to the immediate necessity of implementing HIV testing to women who live in PuHDs (Norman, et. al., 2008). Again, as mentioned above, this self-reported rate is four times the rate of the estimated HIV

prevalence among all adolescent and adult women living in Puerto Rico, according to the data provided by the Centers for Disease Control (CDC, 2010). As such, Pfizer Pharmaceuticals was approached with the data findings and they supported the project, awarding a two year contract to test 375 female residents of PuHDs.

Fortunately, by this time, the women knew who the research team was and no problems recruiting participants emerged. The team only had to visit four randomly selected PuHDs to recruit 386 women. Due to the logistics of the testing and the inability to go to the women's apartments due to safety issues, the testing had to be conducted in the community center. However, this did not deter the women from coming and participating. The research team was only able to test 50 women per day, so it went to each of the four randomly selected PuHDs two times. At the present time, only two HIV positive women ( $2/386 = 0.01\%$ ) have been identified. The research team believes that the women who were already positive are choosing not to come because they don't see the benefit of being retested, even though STI testing (for chlamydia and gonorrhea) is offered. Consequently, the project plans to distribute additional information about the importance of retesting and STI testing in the flyers to encourage this continued participation; plans are also in place to develop information for male residents. This has not been done yet, but the plan is to go testing in the very near future to one of the largest PuHDs here in Ponce; it is one that was not visited during the formative research phase of the project.

As mentioned above, men will also be invited to participate, since 11 women tested positive for chlamydia and one tested positive for gonorrhea (2.9% and 0.03%, respectively) (Norman, et. al., 2011). It is believed that the men are the vectors of the infection for these women and, as such, the research team needs to get them tested and referred into treatment as a way to prevent further transmission to the female residents of PuHD here in Puerto Rico.

At this time, the team has not tested anyone using this new protocol. However, it is believed that the project will be successful in the continued recruitment of women as well as men in our project, if the previous success record is any indication. The project is currently funded by the RCMi program at NIH (grant # G12RR003050 awarded to the Ponce School of Medicine and Health Sciences from 2009-2014) to test another 375 residents of public housing as well as to examine the social epidemiological factors associated with the increased HIV/STI risk and prevalence among members of this population.

### **2.2.3 Recruitment strategies used in *Proyecto MUCHAS***

Initially, the recruitment strategies were not very effective. At the PuHD first visited (Lopez Nussa) to collect the quantitative formative data, only 15 women showed up. The research team had placed flyers up at the PuHD to announce the date coming. By this time, the logo and name were developed, as described above. Needless to say the team was very disappointed. However, a research assistant suggested the idea to use the PuHD's megaphone to drive around the complex and let the women know the team was there, and to invite them to come down and participate. This resulted in approximately an additional 75 women coming down to the community center and completing the survey. So this is the strategy that was used when approaching the other PuHDs, especially the large ones. A megaphone was purchased rather cheaply and it was very effective in the beginning to get

the women to come down during the day, especially at the time the novellas (Spanish soap opera) are being aired on the local television channels. The research team had already been told that this would probably be a barrier to women's participation. However, the number of women reached in five months suggests it was not a barrier. Overall, this proved the most effective strategy employed to recruit women into the study during the formative phase of the research process. An example of the effectiveness of this strategy lies in the following: over 200 women showed up at Dr. Pila, the largest PuHD here in Ponce, PR. The team actually ran out of questionnaires and had to cut off data collection even though there were still women who wanted to participate. By this time, word had spread throughout the various PuHDs, providing information about the project so that women began to recognize the logo and project name. As such, this resulted in the residents accepting and trusting the project team, and being willing to participate. As a result, data were collected from 1138 women on the quantitative questionnaire. Using the data collected from the quantitative instrument, a qualitative instrument was developed to probe a bit deeper into some of the findings revealed from the analysis of the data set (e.g., their perception of risk, since most women reported being a no risk (approximately 50%)). A convenience sample was used to identify 150 women from various PuHDs, to ensure that there was someone from every PuHD that had been previously visited was included in the sample. As such, all women approached agreed to participate in the face-to-face interview, which took on average between 60 to 120 minutes to complete.

### **2.3 Obstacles faced during the implementation of *Proyecto MUCHAS***

The project was not without obstacles. The major obstacle faced dealt with the safety issue of the project team performing the research in the PuHDs. However, inner-city, low-income PuHDs are an appropriate and important setting for HIV/STI formative research and subsequent HIV risk reduction interventions. They constitute identifiable and accessible communities in which women at risk for HIV/STI infection can be reached. Characteristics of PuHDs, such as their accessibility, the potential for multiple contacts, and the formulation of resident-controlled intervention components, increase the likely efficacy of such HIV-prevention programs.

This strength, however, is directly related to the major impediment. PuHDs are well-known to have high rates of crime and violence, as well as illicit drug use. Puerto Rico has the highest murder rate in the U.S. and its territories, and 60% of those murders are linked to illegal drugs (Rosa, 2005). The extreme levels of drug-related crime and violence found in PuHDs inevitably contribute to the elevated rates of crime and violence in the overall crime rate in Puerto Rico (Barcelo, 2004). As such, the administration does not allow the research team to go to the residents' apartments and to do the testing and data-collection in private. The team has to go during the day, between the hours of 10:00 a.m. and 7:00 p.m., which are the hours that the administration office is open.

However, the administrative staff has been very helpful, assisting with signing women up and keeping order in the method of data collection, including the testing process. They are also able to identify any person who is not a resident of that specific PuHD but may be trying to participate in the study. As such, this obstacle has weakened the research design, by not allowing the research team to use a random design that was originally proposed. Nevertheless, PuHDs are randomly selected and then every eligible resident is invited to

participate. Under the circumstances, this is the best and the strongest design that can be employed, given the realities of the safety issues associated with being in the PuHD.

An example of this concern is illustrated by the following: there were two homicides (both drug-related) that took place last year at the next scheduled site to visit and to conduct HIV/STI testing. Previously, a police officer at this site had expressed his concern for the team's safety and he volunteered to accompany the research team around the complex. This offer was respectfully declined because of concern that it would dissuade participation if team members were accompanied by the police because of fear about informants related to drug use, which is very prevalent in this particular PuHD. Also, associating with the police in front of residents puts the team at increased risk of becoming a victim of drug-related violence.

Overall, residents have been very responsive. The PI had previously conducted some observational research on non-injecting drug use among the residents, to present these data at International Harm Reduction Association Annual Meeting in Warsaw, Poland, in April 2007. During this seven-hour observation, men openly smoked while others bought drugs. Yet, they made the PI feel very comfortable and safe while she was there. One of the men who was there was also a dealer but he trusted the PI to not "narc" on him. Unfortunately, he was one of the victims that got shot last year.

This acceptance and trust is vital for the success of a project like this; this also facilitates the willingness of residents' acceptance of and participation in the research project. The residents have been very accepting and trusting, and the team wants to maintain this relationship. Residents recognize the project logo and name and will come down to participate without further use of the megaphone. The team simply puts some posters/flyers up at the mailbox section of the PuHD about a week or two before the site visit, and then when the team arrives, there are many more women waiting to be tested than can be completed in one day. This has been another obstacle faced, along with the realization that we have to work out a way to where we can test the residents in two consecutive days, so they do not get discouraged and are unwilling to come back. However, this issue has to nothing to do directly with the research project but with the disbursement of money from the PI's institution. The research team is currently working with them to resolve this issue.

#### **2.4 Lessons learned from participating in *Proyecto MUCHAS***

Important lessons have been learned during the development and implementation of this project. The most important lesson learned is that it is imperative to treat the residents with respect and not to be judgmental. They respect the team and the team respects them. It was expressed during the focus groups, which were conducted during the formative phase of the research project that they didn't want someone coming over in an "Armani suit" or carrying a "Gucci" handbag trying to talk to them about what it is like to live in a PuHD, because they could not even begin to understand what these residents face and what it is like to be impoverished, with very limited opportunities for betterment (Abreu, et. al., 2010). As such, even if the team is from the Ponce School of Medicine and Health Sciences, it tries to treat them as equals and never pass judgment, even in light of socially undesirable responses (e.g., 95% of the women are unemployed, and only 11% and 22% report using



condoms with their last steady and non-steady sex partner) (Norman, et. al., 2010). It is necessary that women feel comfortable enough to share this information, in that these are essential characteristics that keep them in poverty as well as continuing to engage in high risk sexual behaviors. These behaviors include having multiple sex partners, as well as very low rates of condom use reported, and anal intercourse with both steady and non-steady sex partners. In addition, the research team asks about drug use, both a history of and current drug use, which is quite stigmatized, especially among women in PR-- but again, the team does not pass judgment on those who admit a history or current use of illicit drugs, such as heroin and crack-cocaine.

The project team has also learned that these residents want to know more about HIV prevention and strategies to keep them safe. The PuHD administration, based on requests from their residents, has asked the team to prepare and deliver a knowledge and skills-building workshop targeting toward to the PuHD residents to improve knowledge, attitudes, and provide skills in assessing their personal risk of contracting HIV as well as negotiating condom use with their sex partners. This is a positive lesson, in that these women have expressed not only an interest but a desire and willingness to participate in an intervention--if one is developed and implemented targeting them.

In addition, it has been learned that these women have been ignored in previous HIV-related research efforts. As mentioned above, only one study was identified that targeted female residents of public housing and that was almost 20 years ago (Hunt, et. al., 1993). These women are in dire need of HIV prevention interventions, based on their self-reported HIV prevalence rates being over four times of that of the general population of women of the same age group as well as their rates of reported high-risk behaviors. Most HIV-related research has focused on injecting drug use or sex work in and around the San Juan, PR area, especially since injecting drug use is the major mode of HIV transmission among men. However, heterosexual transmission is the major mode among women, constituting approximately two-thirds of all cases (PR Department of Health, 2011). It is an ignominy that no one has recognized the need of these women to receive additional HIV prevention interventions, including continued testing of HIV and other STIs. Residents are highly appreciative of the project and have become very willing to participate. The research team attributes most of the success of this project to date to the participants or residents who live in PuHDs. Without their acceptance of the team and their willingness to participate, the project would not have been able to reach as many women.

### **3. Recommendations based on our experiences in *Proyecto MUCHAS* and other relevant research**

A number of recommendations can be made from the research team's experience with *Proyecto MUCHAS*. The first recommendation would to treat the study population with respect. This is a critical element in implementing a successful HIV-testing outreach project. Related to this recommendation, the researchers should never be judgmental of a participant's responses, even if they do report illegal or socially irresponsible behaviors. It is vital that participants feel comfortable providing these type of sensitive data. A second recommendation is that any potential research project targeting a similar population should be pro-active and aggressive in their recruitment strategies. There are times when traditional



recruitment strategies are just not as effective as they need to be. When this happens, a researcher has to be willing to step outside their comfort zone and try something new and innovative, which is what the research team of *Proyecto MUCHAS* did, and it proved to be very successful. And the researchers should never assume that participants are unwilling or uninterested in participating in an intervention, if they believe it will be beneficial to them. However, as mentioned earlier, whomever is chosen to deliver this workshop must be credible but also be accepted and trusted by the participants or they will not trust any information that is being presented to them. The workshop coordinator/presenter must be willing to speak at a level that the participants can understand, as well as show empathy for participants who may be facing extraordinary obstacles to practicing safer sex within their sexual relationships. Also, the team would recommend that each research project develop a logo and a name that participants can associate with the project. The *Proyecto MUCHAS* project developed the logo and name before we ever conducted any data collection (including both the qualitative and quantitative formative data collection). Through the dissemination of information, it will ultimately increase participants' acceptance and willingness to take part in the research project.

#### **4. Implications for future research using this model (*Proyecto MUCHAS*)**

There are a number of implications that have arisen from the experience in the development and implementation of *Proyecto MUCHAS*. First, it is important to recognize the vulnerability of public housing residents or low-income and impoverished persons. Research with female public housing residents in the U.S. provides evidence of this vulnerability (Sikemma, 1996; 2000). However, this project focused on prevention of HIV by promoting behavior change. A new paradigm has emerged, which views treatment as a prevention method. This new paradigm, most aggressively led by Julio Montaner, Clinical Director of the BC Centre for Excellence in HIV/AIDS in Vancouver, is frequently referred to as the *Seek-Test-Treat-Retain* strategy (Volkow & Montaner, 2010). The strategy has taken shape as multiple ecological studies emerged, showing the effectiveness of antiretroviral treatment in reducing HIV transmission (Anglemyer, et. al., 2011; Montaner, 2011). In May 2011, results of an NIH-funded trial of this approach known as HPTN 052, filled important gaps in the evidence on efficacy (HIV Prevention Trials Network, 2011). However, it is important to emphasize that HIV treatment is only one of the aspects of HIV prevention efforts that should be targeted toward disadvantaged women. Informing a person of his/her HIV status is the first step. For those who test negative, they are given informational brochures on how to keep from contracting HIV. For those who test positive, we refer them to treatment, along with providing post-test counseling. This post-test counseling includes information on ways they can preventing transmission on to potential sex partners as well as how to protect themselves from re-infections. HIV prevention programs targeting this population must be multi-faceted, including HIV education and skills building, along with HIV testing and following up for treatment for those who test positive.

The result of these developments is that there will be renewed efforts to aggressively implement HIV testing and retention interventions in non-traditional settings (IRIN, 2011). The impetus is not only the need to address significant disparities related to the HIV epidemic, but also the continued lack of substantive progress in the number of people aware

of their HIV status, and if positive, linked, and retained into care. Across the most recent studies, approximately one-third to one-half of the newly diagnosed do not connect to care in the post six month period. One in five people who are HIV positive remain unaware of their status in the U.S., with worse estimates for disproportionately affected populations, including those in developing countries (Morin, et. al., 2011). It is important to note that a recent CDC study documented that, similar to the developing world, the U.S. now as a generalized epidemic in urban poverty areas, where four to five times more ethnic minorities reside compared to white (Denning & DiNenno, 2010). However, it is important to recognize that treatment is just one aspect of future HIV transmission. It is to be included in a comprehensive HIV prevention program, first by testing women and informing them of their status. Secondly, HIV prevention information is given to women who test negative but continue to engage in high-risk behaviors. For those that test positive, we refer them to treatment, with treatment now being considered a prevention method for reasons mentioned above. A comprehensive, multi-faceted HIV prevention program is needed for female residents of public housing.

A paradigm of early treatment is still dependent upon early detection, placing even more emphasis on developing innovative strategies of seek and testing and in addressing the acute infection period (Powers, et. al., 2011). However, despite the CDC's nation-wide push to implement routine HIV testing, less than one-third of patients are offered such testing, even where it has been adopted; less than 70% accepted the test (Morin, et. al., 2011).

This is why the success of *Proyecto MUCHAS*, is promising in utilizing a non-traditional setting, removing many obstacles and barriers that persons, especially impoverished minority ones, face. Hopefully, this is just the beginning of an HIV-testing campaign to test all eligible residents of PuHD's in Ponce, PR, and eventually to those in the Southern Region, where approximately 17% of all reported HIV cases exist (Puerto Rico). At this time there are 35,000 residents who live in 73 PuHDs in the Southern region of PR, where Ponce is located, including women and men, adolescents and adults. There is also potential for this study to be replicated in other impoverished communities in PR as well as outside of PR. This model could be applicable with proper cultural adaptation to other countries as well, since subsidized or publicly provided housing is both the norm and highly understudied and underutilized as a venue to HIV prevention.

#### **4.1 HIV engagement or treatment cascade**

Another implication is related to the HIV Treatment or Engagement Cascade, which was referred to earlier in the chapter. The strategy of testing and treating as many HIV-positive individuals as possible as a primary prevention strategy has received a great deal of recent attention and advocacy (Dieffenbach CW, Fauci AS, 2009; Granich, et. al., 2009). Universal, voluntary HIV testing has been proposed to identify persons with undetected contracted HIV infection as well as those who are diagnosed but not receiving treatment. Once identified, people diagnosed with HIV should be promptly entered into care and encouraged to initiate and maintain ART regimens to produce viral suppression. In addition to the personal health benefits derived from early HIV identification and treatment, ART that successfully suppresses viral load has been shown to reduce the efficiency of onward

disease transmission from infected persons to their sexual partners (Quinn, et. al., 2000; Velasco-Hernandez, Gershengorn HB, Blower SM 2002). Consequently, universal and voluntary HIV testing and antiretroviral treatment of people with HIV is seen as a promising strategy for reducing infectivity and lessening the likelihood of disease transmission (Dieffenbach CW, Fauci AS, 2009; Granich, et. al., 2009). Again, this highlights the importance of testing members of a potentially high-risk of HIV. As such, using *Proyecto MUCHAS* as a model for developing a research project for reaching these impoverished persons may provide the data needed to move HIV-positive participants through the stages of the engagement cascade (Gardner, et. al., 2011). See Figure 3 below for a graphic illustration of the engagement cascade with respect to HIV care.

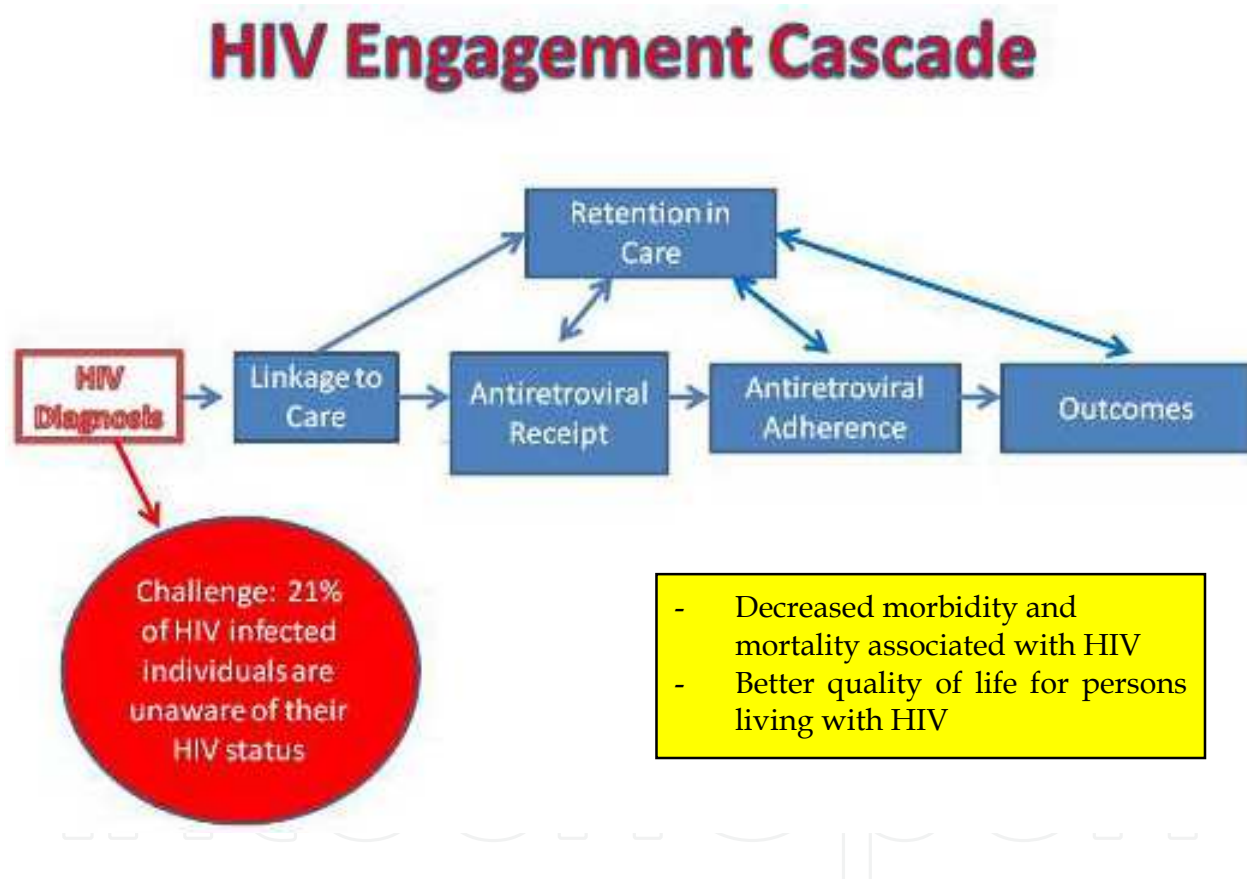


Fig. 3. HIV Engagement Cascade Flowchart

If you notice, HIV testing and diagnosis is highlighted in red, as an indication of its importance in the cascade.

Without HIV testing and informing persons of their status, no further progression can be made with respect to the cascade. HIV testing is the first and can be argued to be the most important step in getting HIV-infected patients linked to and retained in appropriate HIV care and treatment.

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It can be said that now is the best time for everyone infected to become aware of their own HIV status. The state of the art in HIV management progressively reveals that antiretroviral treatment can prevent transmission, as well as chronic damage in the human body, if started early. Unfortunately, antiretrovirals are not widely available in many places, especially in developing countries. In these parts of the world, diagnosis of HIV infection must be kept in the agenda as a priority, in order to understand specific details of local epidemics and as an effort to interrupt the chain of HIV transmission.

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