ABSTRACT

Title of dissertation: COORDINATED HIV PREVENTION ACROSS DOMESTIC JURISDICTIONAL BORDERS

Denise Marie Bellows, Doctor of Philosophy, 2015

Dissertation directed by: Professor Bradley O. Boekeloo
Department of Behavioral and Community Health

Problem: Urban HIV epidemics often span State and County jurisdictional borders; evidence suggests that borders create barriers to coordinated approaches to HIV prevention and treatment. No systematic assessment has been conducted to understand domestic borders and how they are perceived and navigated by HIV prevention stakeholders.

Objective: The specific aims of this investigation are to:

1. Examine the extent to which there are disconnects between services available to vulnerable populations and expertise of HIV Prevention Organizations (HPOs).
2. Describe collaboration between HPOs across a jurisdictional border.
3. Determine whether the Health Services Research Utilization Model (HSUM) explains organizational barriers to coordinated HIV prevention across jurisdictional borders.

Methods: Data from a survey of HPOs were analyzed to explore populations served by HPOs, organizational expertise with vulnerable populations, HPOs perceived benefits and barriers to cross-jurisdictional collaboration, past and current cross-jurisdictional collaboration, and efficacy for cross-jurisdictional grant-writing. Correlations between these constructs were assessed with Spearman's Rho and jurisdictional differences were analyzed with the Mann-Whitney U test statistic. The matrix method of literature review (MMLR) explored organizational barriers to coordinated HIV prevention across jurisdictional borders and the HSUM as a framework.

Results: While 13 of 15 HIV-vulnerable populations were served by over 50% of the HPOs in the study, only 2 of these 13 populations were served with high expertise by more than half of the HPOs in the sample - giving credence to community leader's concerns regarding misalliance between whom HPOs serve and with whom they have high expertise. For a majority of HPOs, inadequate *staffing* and *resources* prevented cross-jurisdictional grant applications. Cross-jurisdiction grant-writing efficacy was associated with fewer perceived barriers (r = -0.642, p<0.01). The HSUM captured all of the organizational barriers to cross-jurisdictional collaboration for HIV prevention, and the MMLR added 14 sub-constructs to the HSUM and operationalized the model for addressing organizational barriers to HIV prevention across jurisdictional borders.

Conclusions: The identification of barriers to cross-jurisdictional collaboration and the validation of a framework for addressing these barriers may aid researchers and healthcare professionals in resolving inefficiencies in HIV prevention services in metropolitan areas that cross jurisdictional borders.

COORDINATED HIV PREVENTION ACROSS JURISDICTIONAL BORDERS

By

Denise Marie Bellows

Dissertation Submitted to the Faculty of the Graduate School of the
University of Maryland, College Park in partial fulfillment of the
requirements for the degree of
Doctor of Philosophy
2015

Advisory Committee:

Professor Bradley O. Boekeloo, Ph.D., Chair
Professor Kerry M. Green, Ph.D.
Professor Donna E. Howard, Dr.PH
Professor MinQi Wang, Ph.D.
Professor Mia Smith-Bynum, Ph.D. Dean's Representative

Dedication

To the amazing PhDs who came before me: Melinda, Keisha, Theresa, Mollie, Sylvette, Ina, Pam, Jessica, and the few I probably missed in this list: I was an undergraduate at the University of Maryland when I watched you struggle through your dissertations. Teaching classes of undergraduate students, overcoming life's challenges and all the while, maintaining a smile and never giving up on your goal of graduating with a PhD. You gave me advice before I was even considering a PhD – most memorable was, "do it while you are young and have the energy!" I didn't understand at the time. You told me life would become more complicated and more stressful as I got older. I was in my 20s and getting 4-5 hours of sleep per night, and could not imagine not having the energy or motivation to finish a degree. I also thought life could not possibly get any more complicated – I was wrong, and you were right! As I journeyed through my doctoral program, I thought of you often. I thought of your advice, I thought of how you managed to go to the gym, teach classes, have a family, all the while working on the most complicated marathon of your life – a dissertation. Though I haven't seen you in a while, you are the heroines I thought of in the times when I wanted to give up. Thank you for being great role models for me and all of your other students who followed in your footsteps.

To my family, especially my Mom & Dad: I know you felt you were on this journey with me all along the way. You gave me space when I needed time to work hard and never made me feel bad about it. You were always there when I needed you close, to help with a move, to supply me with a wardrobe, to fix my broken vacuum cleaner so I would not be living in filth; you did all of this for me, never asking for anything in return. I know this journey was as hard for you as it was for me, and I am sure that at times, you worried that I wouldn't make it. I promised myself I would not let you down. Thanks for being such great role models throughout my life, making me want to achieve great things and make you proud.

To my wonderful husband, Akshay: For providing tough love through the end of my dissertation. For my birthday present – the desk to which I was ordered to sit in until my dissertation was complete! For cups of coffee, late night snacks, hugs and breaks when I needed them. You made it easier for me to complete this work, and you showed me a glimpse of the future we could have together once I finished.

To my future: You are now only a small bump growing inside of me, but I have thought of you for my whole life. Everything I have done up until this point was with the hope that I could eventually provide a good life for you. You came a long at just the right time, when I was looking for motivation to complete my doctoral journey, and gave me the strength to persevere, and a light at the end of the tunnel to look forward to. I hope that my successful completion of this program helps you to realize that you can do whatever you want with your life, as long as you never give up!

Acknowledgements

One of the most important things I have learned during this process is that a dissertation cannot be accomplished alone. .This work would not be possible without cooperation, support, advice, guidance, and acceptance from not only academics in my program, but also from stakeholders in the community this research aims to serve. Sincere thanks and appreciation to Vicki Stovall, Barbara Conrad, Marcia Pearl, Gwendolyn Anderson, Pam Creekmur, Henry Bishop, Irwin Royster, Dedra Spears-Johnson, Rachel Smith, Anne Wiseman, Anne White, and the many others who supported my work. I am also grateful for the support of the Sexually Transmitted Infections Community Coalition and its members, as well as the Prince George's County Health Action Coalition's HIV Task force and its members. Working with you and getting to know you over the past 7 years has been a pleasure, and it has changed me as a person – for the better.

Now the academics, I would like to extend sincere thanks to my committee members, Min Qi Wang, Mia Smith-Bynum, Kerry Green, and Donna Howard. I am also thankful for guidance and support from other academics who believed in me through this process: Nancy Atkinson, Linda Aldoory, Suzanne Randolph, and Kathy Sharp.

Undoubtedly, the greatest thanks and appreciation go to my mentor, advisor, and friend, Dr. Bradley Boekeloo. Thank you for taking me on as a student researcher over a decade ago! You have provided guidance on all things, academic, and non-academic for more than one third of my life! I believe we have accomplished some great things together and though this dissertation is finally complete, I know this does not mark the end of our work together. Thank you!

Table of Contents

Chapter 1 Introduction

1.1 Overview of the Problem

1.1.1 National Recommendations for Improving the Public's Health

The 2012 Institute of Medicine (IOM) report, *For the Public's Health: Investing in a Healthier Future*, makes several recommendations pointing to the need for increased study of how place and public health infrastructure influence the health of the nation. The report provided the following general recommendations for public health system improvement: 1) There is a need for greater coordination between funded health agencies; 2) Public health should have a clinical core; 3) Public health should collaborate to develop evidence-based strategies to address population health needs; 4) Federal agencies should design and implement funding to incentivize coordination among public health stakeholders; 5) collaboration across agencies and organizations (stakeholders) to develop a model for better tracking of funding and related outputs/outcomes across agencies. Additionally, one of the primary goals of the National HIV/AIDS Strategy (NHAS) released by the United States government in 2010 is to achieve a more coordinated national response to the HIV epidemic through increasing coordination of programs between federal agencies and local governments; including improved monitoring and reporting on progress towards national goals. This study examines challenges and opportunities related to public health coordination and collaboration as it relates to HIV prevention stakeholders in the midst of an epidemic straddling a jurisdictional border.

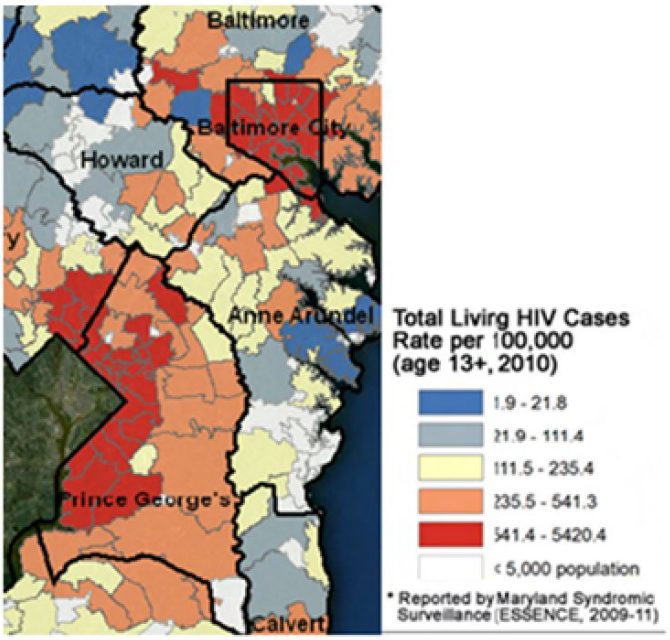
1.1.2 The HIV epidemic in the United States

A recent study modeling the future of the HIV epidemic in the United States projected that without rapid scale-up of HIV prevention services, the HIV epidemic will greatly worsen; the status quo will lead to a 29% increase in HIV prevalence over the next ten years (Hall, Green, & Wolitski, 2010). The rates of HIV/AIDS in suburban communities are generally higher than rural and lower than urban communities (Hall, Li, & McKenna, 2005). Of all United States territories, Washington D.C. had the highest incidence and prevalence of HIV in 2011; similar to previous years (Maryland Department of Health and Mental Hygiene, 2013).

1.1.3 The HIV epidemic in the Case Study Region

In 2011, Maryland had the highest HIV incidence and prevalence among states (Maryland Department of Health and Mental Hygiene, 2013). Maryland's high rates of HIV are mostly attributed to Baltimore County, which includes all of Baltimore City, and Prince George's County, which shares a border with Washington, D.C.

Figure 1.1 Total Living HIV Case Rate



Source: Maryland HEZ Supplemental Data Viewer, http://dhmh.maryland.gov/healthenterprisezones/SitePages/Hez_Resources.aspx

Figure 1.1 shows how HIV rates are distributed geographically in the state of Maryland. Zip codes closest to the Washington, D.C. border are experiencing the highest rates of HIV, within Prince George's County.

Previous studies have found that the spread of HIV/AIDS has occurred from urban to suburban areas mirroring incarceration, residential segregation, migration, commuting, and social mixing patterns (Wallace & Wallace, 1995). The Brookings Institution's Greater Washington Research Program has published a series of articles explaining the growth of the Metropolitan Washington region over the past two decades. The research program has found that HIV/AIDS trends in Prince George's County echo findings of prior studies that 1) identified spread of HIV from urban to suburban communities and 2) correlated HIV rates with indicators of social determinants of health. For example, the greatest net migration in the region is from Washington, D.C. to Prince George's County, primarily in zip codes within the border of the National Capital Beltway (i.e. Interstate 495, which circles the District of Columbia). Those migrating from Washington, D.C. into suburban Prince George's County were black, had lower income than those migrating out of the county, and tended to be foreign-born (DeRenzis & Rivlin, 2007). Concurrent with this migration, poverty rates have decreased in Washington, D.C. and increased in Prince George's County in the period from 2005-2010 (George Mason University Center for Regional Analysis, 2011). With increasing urban sprawl of lower income populations into historically middle-income suburbs, access to social services for lower income individuals and families becomes a major community health challenge (DeRenzis & Rivlin 2007; Allard & Roth 2010). Challenges for the HIV-vulnerable and PLWH in accessing healthcare and other preventative services in the

suburban region are major barriers to preventing new HIV infections. No study has assessed the extent that changing regional demography and nonprofit sector infrastructure impact HIV prevention stakeholders and organizations. This study will investigate HIV prevention stakeholder's perceptions of the growing HIV positive population in the cross-jurisdictional region.

1.1.4 Resources for the largest domestic HIV epidemic

Even with effective, evidence-based prevention programs and life-prolonging medications, there are 56,000 new HIV diagnoses in the United States every year (Centers for Disease Control and Prevention, 2012). This estimate takes the known 47,500 diagnosed with HIV in 2010 and adds 18% to account for those who are positive, but have not received a test confirming that they are HIV positive. Consideration of the resources available and the number of new infections per year raises the concern that prevention programs and treatments are not reaching populations who need them most. The National HIV/AIDS Strategy (2010) proclaims that we have the tools to stop the HIV epidemic, and calls for a coordinated response across programs, agencies, and governments to increase access to prevention and treatment. Federal resources for HIV treatment and prevention are allocated based on AIDS cases, needs, and gaps in services. Funds are awarded by jurisdiction (i.e. state, county, district, Eligible Metropolitan Area (EMA), and Transitional Statistical Area). Federal funding is typically awarded to the urban jurisdiction where rates of HIV are the highest. The District of Columbia, receives direct Ryan White Care Act funding for HIV prevention and treatment in the Washington EMA. These federal funds are intended to be allocated to 19 other jurisdictions covering three states. After Washington, D.C., Prince George's County is home to the majority of

PLWH in the EMA, and is appropriately referred to as, “the region’s second HIV epicenter,” (Mosaica, 2010). Even though federal funding is given to address HIV in the entire region, there is no federal requirement for cross-jurisdictional coordination or implementation with federal funds. Consequently, there are differences in access to care, portability of care, and parity across the region (Mosaica, 2010); indicating that jurisdictional borders impact ability to address HIV prevention and treatment.

In addition to fiscal policy, programmatic policy may contribute to the resource disparity across jurisdictional borders. While Washington, D.C. is a national leader in promoting routine HIV testing in healthcare settings, directly across the border in Prince George’s County, many providers and health care administrators were unaware of the recommendation for routine HIV testing (D.C. Appleseed Report, 2009). Contributing to the challenge is the general strain on service-providing nonprofits in the suburban region. Portions of Prince George’s County experienced more than a 40% increase in the poor population from 2000–2008 (Allard & Roth, 2010). The ratio of poor persons to nonprofit service providers in Prince George’s County was 729 to 1 in 2010, which is more than double the ratio of neighboring Montgomery County (Allard & Roth, 2010). Nonprofit revenue per person is also much lower than in neighboring jurisdictions (Allard & Roth, 2010). So, while suburban regions are experiencing unprecedented increases in poor populations, nonprofit social service sectors may lack the capacity to keep up with these changes. This exploratory analysis will examine the impact of jurisdictional border on HIV epidemics through a case study of the border between Washington, D.C. and suburban Prince George’s County, by investigating stakeholder’s perspectives, activities

and policies related to cross-jurisdictional relationships and responsibilities related to HIV prevention.

1.1.5 Brief ethnography of Case Study Population

A suburb of the Nation's Capital, Prince George's County is renowned for having the highest median income of predominantly nonwhite counties in the United States. The county is 73.4% nonwhite and 65.4% African American, with a median income of $73,447 (U.S. Census, 2012). Similar to other suburbs of the nation's capital, Prince George's County has many high-earning, highly educated, ambitious community members. In addition, the county's majority African American population tends to be socially conservative and highly influenced by faith-leaders (King, 2007; Wooster, 2011). While there is great prosperity in the county, wealth is concentrated in regions of the county furthest from the urban center (DeRenzis & Rivlin, 2007). Neighborhoods in Prince George's County that border one of the wealthiest, most powerful cities in the nation are not experiencing the same financial growth and prosperity as the rest of the county. This region bordering Washington, D.C. is designated a medically underserved area, with only one healthcare clinic serving 38,621 residents (Prince George's County Health Department, 2012). One zip code within the region was recently designated a Health Enterprise Zone; a title that comes with an endowment to reduce health disparities between geographic regions in the state of Maryland (Prince George's County Health Department, 2012). As is evident from Table 1.1 below, Health disparities exist in the county for many other conditions (i.e. heart disease, chlamydia); however, the disparity in HIV is the largest.

Table 1.1: Prince George's compared to State of Maryland in Rates per 100,000.

Disease/Condition	Prince George's County	Maryland Average
HIV, new cases, 2011[1]	45.9	26.9
Chlamydia, new cases, 2011[2]	698.6	466.0
Heart Disease deaths, 2010[2]	223.7	182.0
Number of PCPs[2]	53.9	84.5

Source: Data compiled from: Maryland HIV/AIDS Epidemiological Profile Fourth Quarter 2012,[1] Maryland State Health Improvement Plan 2012 Update[2]

As recommended to address poverty in the region (DeRenzis & Rivlin, 2007), Prince George's County is striving to maintain an image that will attract new business and highly skilled service providers to the county and also keep higher-income households from leaving the county. To do this, the county habitually dedicates public funds to education and safety, leaving little funds to address poverty and public health. For these reasons and others yet to be identified, it is important to understand the environmental and structural context of this region prior to planning how to strategically address all of the factors influencing high rates of HIV.

1.1.6 Challenges related to jurisdictional border

Borders create a unique community dynamic, because while a community may share culture, geography, socioeconomic and health status, division by political border may add challenges to successful collaborative efforts between service entities in the community, especially those dependent on public funding. Public funding, more specifically federal funding, is still carrying the financial burden of prevention of sexually transmitted infections, like HIV (ASHA, 2008). These public funds are allotted

in each jurisdiction based on the political will of the state, as well as availability of funds from Congress (Sarpal, 2009).

Prince George's County's lack of investment in HIV is not necessarily a dismissal of the issue. The plethora of resources for HIV in the two urban epicenters to the North and South of the County could lead stakeholders to believe that the HIV issue is being addressed. It is not unreasonable to think that individuals in the county could benefit from resources in these major cities. Unfortunately, this ignores the reality of challenges related to poverty, public health infrastructure, and resource allocation; specifically in Baltimore, and Washington, D.C.

For those with access to transportation, HIV prevention and treatment resources in the two urban epicenters may be accessible; that is, if organization policies permit non-residents to utilize these resources. For those with private insurance, access may also be less of an issue. For those experiencing poverty and other extreme stresses, there may be a greater need for resources to be closer to home. Populations most impacted by HIV tend to be the most vulnerable to issues of resource access (Sumartojo, 2000; Rhodes, Wagner, Strathdee, Shannon, Davidson, & Bourgois, 2012). These populations include: sexual minorities, individuals with substance abuse challenges, migrant populations, and individuals with medical and mental health disabilities (Sumartojo, 2000; Rhodes, Wagner, Strathdee, Shannon, Davidson, & Bourgois, 2012; Aday, 2003).

1.1.7 Borders and Health

In the United States, Local Health Departments (LHDs) are increasingly reporting resource sharing with other LHDs and other organizations (NACCHO, 2013). However, the majority of the literature focuses on migration and transnational health, specifically in

the United States - Mexico border region and Eurasia. Studies on U.S. domestic jurisdictional borders and health remain scarce. In addition, existing theory on the impact of jurisdictional border on health, and more specifically HIV, is limited.

Studies of the U.S. Mexican border have identified transnationalism as a challenge in addressing infectious disease outbreaks. It was in this U.S. – Mexico border region that public health first recognized that infectious diseases could not be addressed in this migrant population without treating populations on both sides of the jurisdictional border. Most of these studies examine aspects of health of a population across international borders. For example, one study of HIV/AIDS patients residing within two miles of the U.S. Mexico border (i.e., on each side) identified challenges created by the border in four categories of service utilization: availability, accessibility, acceptability, and accountability (Zuniga, Organista, Scolari, Olshefsky, Schulho, & Colon, 2006), based on the Behavioral Model of Health Service Utilization (Aday 1995 as in Zuniga et al., 2010). While international borders pose different challenges than domestic borders, theoretical concepts and lessons learned from studies of international borders and health may be applied to domestic border health issues.

While there have been many notable studies of borders and health in Eurasia, a questionnaire by the Istituto di Sociologia Internazionale di Gorizia (ISIG) in 2009 examining national borders in the Mediterranean and their impact on health systems produced results applicable to our domestic study of borders and health. Consistent with what is known about boundary theory (Schrank, 2006), ISIG determined that borders can range from being hard or soft, permeable or impermeable; thus, re-definition of borders is necessary when they become too hard or too soft. Health system variables, such as

efficiency, effectiveness and functioning are altered by borders because of: 1) gains on one side of the border not available on the other side, 2) quality of public health services may be worsened by the failure of national health systems to overcome borders in organizational terms, 3) border-based discriminatory practices may be implicitly accepted out of consolidated unilateral interpretations of identity (ISIG, 2009).

Organizational collaboration has been suggested as a mechanism for health systems to overcome these border challenges (ISIG, 2009; Libbey & Miyahara, 2011; Busse, Worz, Foubister, Mossialos, Berman, 2006). Organizational collaboration requires overcoming geographic borders by 1) increasing social networking and social ties, 2) reducing the need for transportation, and 3) providing technology solutions to collaborative activities (Boh, Ren, Kiesler & Bussjaeger, 2007). In 2006, the EpiSouth Project was started as a framework for transnational collaboration for communicable diseases surveillance and training in the multi-jurisdictional, Mediterranean Region. The network succeeded in creating cohesion, mutual trust and concrete collaboration on cross-jurisdictional public health issues not addressed by any other initiative or organization in the geographical area (Dente, et al., 2009). The EpiSouth Project is one example of how cross-jurisdictional collaboration can improve public health infrastructure in a region. Other studies have found that using telemedicine; hospitals can offer medical services across borders and in "wide teams." Some of the outcomes to be expected by use of telemedicine to address border issues include: 1) overcome geographic restrictions 2) improve quality of services provided 3) reduce costs of resources 4) reduce patient expenses 5) reduce time and costs of hospitalization, and 6) creation of a medical database, allowing comparative studies and statistical analysis (Spyrou, et al., 2008).

In the 2013 National Profile of Local Health Departments, the National Association of County & City Health Officials has dedicated an entire chapter of the report to Jurisdiction, Governance, and Partnerships. The report explains that though Local Health Departments (LHDs) may differ in governance, they "*work closely through cross-jurisdictional sharing of services*," (NACCHO, 2013). The report indicated that LHDs view cross-jurisdictional sharing as a way to increase efficient and effective delivery of public health services (NACCHO, 2013). In a study sampling 2,532 of the estimated 2,800 agencies meeting the description of a Local Health Department, 42% reported an increase in resource sharing than in the previous year (NACCHO, 2013). Resource-sharing occurred by sharing staff, services, and equipment; sharing occurred most among LHDs governed by a state, and medium-sized LHDs were more likely to provide services to smaller-sized LHDs (NACCHO, 2013).

The relationship between international borders and health is clear, given studies of the U.S. – Mexico border and studies of nations in the European Union. In the United States, interest in coordinated public health across jurisdictional borders is apparent. Still, there is more to be learned about how these borders specifically impact our ability to address increasing transmission of HIV.

1.1.8 Borders and HIV

Though HIV is a global pandemic, in the United States, 40% of infections are concentrated in approximately a dozen local urban epidemics (See Figure 1.2 below), many of which span State and County jurisdictional borders (CDC, ECHHP, 12 cities).

Figure 1.2: Map of Urban HIV epidemics in the United States

Source: Blog.AIDS.gov, The 12 Cities Project. Available at http://blog.aids.gov/2011/02/the-12-cities-project.html

Surveillance studies repeatedly show HIV concentrates in certain populations and even in certain social networks. Often times, these networks and areas are enclosed by geographic or political borders. Several factors have been explored as contributors to the impact these borders have on HIV concentration. Factors involving the HIV infected or affected person include population migration and transnationalism. Program collaboration and service integration has been identified as provider or system-level factors influencing HIV prevalence in certain regions.

Public health researchers are paying attention and the relationship between human mobility and population health. MacPherson, Douglas and Gushlak have created a list of 20 highly mobile populations in which infectious disease are over-represented, including, but not limited to: international students, military, refugees, sex tourists, trafficked migrants, immigrants, diplomats, and business travelers (2011). This relationship between migration and disease is not new – nearly 500 years ago, the spread of syphilis from the New World to Europe was one of the first know examples of the globalization of disease (Harper, Zuckerman, Harper, Kingston, & Armelagos, 2011). However, as the populations grows, the reasons for travel grow, and travel becomes easily accessibility to

the majority of the world's population, the spread of disease becomes more prevalent, and eradication of disease – even more complex and difficult. In 2002, Soskolne and Shtarkshall developed a framework relating population migration and HIV infections, in order to improve HIV prevention efforts of organizations working with migrant populations. They hypothesized the following model: migration leads to SES and power inequalities, which thus limit social capital; bi-directional interactions of cultural norms lead to loss of culture, migration stress, and depleted psychosocial resources; depleted psychosocial resources and limited social capital lead to low use of HIV prevention care and services, elevated risk behaviors, and finally, HIV infections (Soskolne & Shtarkshall, 2002). This framework emphasizes that migration alone is not the predictor of HIV infection, but the environmental and psychological stressors that often accompany migration can make migrants more vulnerable to HIV infection than other populations. In 2008, Thurka Sangaramoorthy points out that migration and HIV/AIDS are "complex and pressing issues," however; studies on these topics remain scarce (Sangaramoorthy, 2008). Studies of migration have looked at migrants as vectors for disease transmission, because greater mixing of diverse groups increases opportunity for introduction of new disease. However, studies are not often considered that migrants are affected by social inequalities and oppressions that create additional barriers to accessing healthcare and social service resources (Sangaramoorthy, 2008). For example, HIV/AIDS programmatic rules and regulations may require certain paperwork and personal information that migrants either do not have or do not want to provide for fear of deportation. This creates challenging situations where either those migrants do not get served, or providers have to

improvise and risk professional wrong-doing in order to care for this migrant population (Sangaramoorthy, 2008).

Another type of migration across borders is transnationalism – the ways in which cultural flows, social imaginaries, and political-economic structures shape and influence the movement of people, ideas and objects (Sangaramoorthy, 2008). Transnational communities migrate across political borders for economic advancement and social or political recognition (Sangaramoorthy, 2008). Recent studies of those seeking healthcare in the U.S. – Mexico Border region have identified, "transnational medical consumerism," which is the population's attempts to optimize their health by using resources available in both countries (Miller-Thayer, 2010). Transnational medical consumerism has been found to have economic benefits not only for the people who access healthcare, but also for the medical markets of the countries providing care (Miller-Thayer, 2010)! Another study of the same U.S.-Mexico border population also found that people cross national borders for care when treatment options are unavailable in their home country, and when there are high levels of provider and social stigma for a particular disease or health problem (Zuniga, Organista, Scolari, Olshefsky, Schulho, & Colon, 2006). These same concepts should be explored through domestic borders.

A critical component of HIV care and treatment is the continuum of care from home to healthcare facilities throughout the duration of infection (WHO, 2002). A community's ability to link with outside services and institutions to create an infrastructure of continuous care for the patient is an important determinant of its capacity for addressing HIV and other health issues (WHO, 2002). WHO recommends strategic linkages, partnership development and collaboration between health and social

services and the communities they serve in order to provide the best possible care to the community. More recently, the Centers for Disease Control and Prevention issued a White Paper articulating specific frameworks for collaboration and service integration between public health infectious disease services, including: surveillance, training, laboratory services, partner services, behavioral interventions, and health education messaging (CDC, 2009). Creating community-health system partnerships can be difficult when the HIV community spans a jurisdictional border. Also, jurisdictional border migration may impact the collaborative interactions between health services and the community. Thus, there is a need for research to identify and address the HIV prevention and treatment barriers posed by jurisdictional border (Conference on Advancing the National HIV/AIDS Strategy in Greater Washington, 2012).

1.2 Hypothesized Conceptual Framework

1.2.1 Theoretical Underpinnings – Social Ecological Model

The Social Ecological Model is a health behavior theory based on systems theory, which distinguishes different social and ecological levels of public health. Social Ecological Model incorporates individual and interpersonal level factors (micro-level factors) but acknowledges the importance and impact of broader socio-cultural factors, such as organizations, community and policy (i.e. macro-level factors), to better explain human behavior. The levels of the social ecological model are individual, interpersonal, community, and societal (McLeroy, Bibeau, Steckler & Glanz, 1988). The theory states that addressing health behavior requires attention to more than just one level social ecological level or system, and requires understanding of the interaction between each level of the model. Elements in the community that may influence health include

schools, public services, public works, local social norms or customs, local history, local policy, or other structures or institutions that have leadership or influential roles on individuals in a community. McLeroy and colleagues have operationalized the community level of Social Ecological Model three distinct ways; however, only two of those operationalizations will be considered in this study. Stemming from McLeroy's operationalization, community can be the relationship between organizations (e.g. local schools, community centers) and groups within an area, or a geographic and politically defined area, where the members of the community are under the jurisdiction of a power structure like a county or city government (McLeroy et al., 1988). In the present study, community will refer to the relationships between organizations in a geographic, politically defined area, where community members are under the jurisdiction of a power structure. For HIV prevention and treatment, government and organization policy can influence access to resources such as prevention and treatment programs, free condoms, needle exchange, sexual health education, and free testing services. The Social Ecological Model states that environmental factors are inextricably linked to the health behaviors of the individual (Bronfenbrenner, 1979; McLeroy et al., 1988; McQuiston, Choi-Hevel, & Clawson, 2001); and provides a framework for examining how policies, programs and resources for HIV prevention and treatment are impacted by a jurisdictional border that divides a community severely impacted by an HIV epidemic.

Organizations are at the meso-layer of the model Social Ecological Model. They are impacted by the community level as well as the policy level. Since the goal is to improve collaboration and coordination between organizations and agencies who have the potential to or currently provide HIV Prevention services, this requires attention to

how organizations work together with other agencies as well as how they are serving the population

1.2.2 Theoretical Underpinnings – Border Theory

The literature on Border Theory is sparse and spans several disciplines with very different perspectives and utility for various border theories. Border Theory is found in Feminist studies (Anna-Liisa Aunio, 2009; Naples, 2009; Naples, 2009a; Anzaldua, 1987), family and social science (Desrochers, 2002; Fox & Guglielmo, 2012; Matthews & Barnes-Farrell, 2010), political science and cultural studies (Vila, 2003; Orozco-Mendoza, 2008; Bernasconi, 2012), and more recently, studies of public health (Ingram, 2005; Cohen, 2005; Steinfelt, 2005; Pinto, 2012; Zuniga, 2012). There are several themes which emerge from the literature on border theory, including, but not limited to concepts related to ***cultural differences*** (Anna-Liisa Aunio, 2009; Naples, 2009; Naples, 2009a; Anzaldua, 1987; Fox & Guglielmo, 2012; Matthews & Barnes-Farrell, 2010) and ***political and economic differences across borders*** (Vila, 2003; Orozco-Mendoza, 2008; Bernasconi, 2012). When exploring borders and HIV prevention, many of the articles focus on access to services and how borders are navigated to attain services that are culturally appropriate, accessible and affordable to those in the border region (Pinto, 2012; Stefl & Prosperi, 1985; Puentes-Markides, 1992; Blank, Fox, Hargrove, Turner, 1995; Gruskin, 2008; Gruskin, Bogecho, Ferguson, 2010; Zuniga, 2012). It was from this body of literature that the analytical model for this research was identified. In a 2010 study of the U.S. – Mexico border region, Zuniga ML and colleagues used a four-part theoretical model of service utilization to collect and analyze qualitative data about barriers to recruitment of the border population into clinical trials. The four components

of the model are availability, accessibility, acceptability and accountability. Several renditions of this model exist in the literature from 1985 to the present date, with most mentioning at least three of the four dimensions of health service delivery (Stefl ME & Prosperi DE, 1985; Puentes-Markides C, 1992; Blank MB, Fox JC, Hargrove DS, Turner JT, 1995; Gruskin S, 2008; Gruskin S, Bogecho D, Ferguson L, 2010). Blank, Fox, Hargrove and Turner came up with the exact same four dimensions as obstacles to effective mental health service delivery in rural areas in 1995. As part of a new 'rights-based' approach to health policies and programs, in the year 2000 the United Nations Committee on Economic, Social, and Cultural Rights called "availability, accessibility, acceptability, and quality of services" the underlying determinants of health which should be assured to all people. Though the U.N. labeled their fourth category "quality of services," the construct is still closely related to "accountability," which is in the Zuniga model, but was left out of the U.N. model. After the Zuniga 2006 article, Sophia Gruskin, editor of the American Journal of Public Health specifically pointed to availability, accessibility, acceptability and quality as key barriers to sexual and reproductive health (2008). As evidenced from the literature, this analytic model will build on previous research to understand whether and how these four dimensions are barriers or facilitators to healthcare, specifically when investigating a population crossing jurisdictional borders. In addition to being relevant to HIV organizations and HIV services, definitions of the four components of the model will also reveal that these components incorporate constructs identified in border theory literature. For the purpose of this study, the following definitions will be used for availability, accessibility, acceptability, and accountability:

1. Availability. Availability will be defined according to Zuniga, et al. as "the existence of services" (Zuniga, et al. 2010). For example, "Are services available in the geographic area?"

2. Accessibility. Zuniga does not specifically define accessibility; therefore the U.N. General Comment No. 14 definition of accessibility will be used. These four overlapping dimensions which define accessibility were also used by Sophia Gruskin and colleagues when the adopted the term for the field of sexual health (Gruskin, Bogecho, & Ferguson, 2010). According to U.N. General Comment No. 14, accessibility:

> *"Encompasses four distinct components, all of which require special attention to the most vulnerable and affected populations: (i)* Non-discrimination*: Health facilities, goods and services must be accessible to all; (ii)* Physical accessibility*: Health facilities, goods and services must be physically accessible to all; (iii)* Affordability*: Health facilities, goods and services must be affordable for all, yielding accessibility of needed services, whether privately or publicly provided; and (iv)* Access to information*: Includes the right to seek, receive, and impart information and ideas concerning health issues, but does not impair the right to have personal health data treated with confidentiality."*

3. Acceptability. The U.N. General Comment No. 14 defines accessibility as, "all health facilities, goods and services must be respectful of medical ethics and culturally appropriate, as well as designed to respect confidentiality and improve the health status of those concerned." Gruskin, Bogecho, & Ferguson emphasize that health facilities, goods and services must be, "sensitive to sex and life-cycle requirements," which is also

included in the UN definition. The 2006 study by Zuniga and colleagues defined acceptability as, "how congruent services are with client expectations (cultural)," and operationalized this definition as including consideration of social expectations, language needs, client comfort, as well as addressing potential stigmas.

4. Accountability. The definition of accountability will come from Gruskin et al. 2010, where *accountability* is defined as being responsible to the community for actions which impact health and development. Accountability mechanisms monitor compliance and support governments in fulfilling their human rights obligations (Gruskin S, et al., 2010).

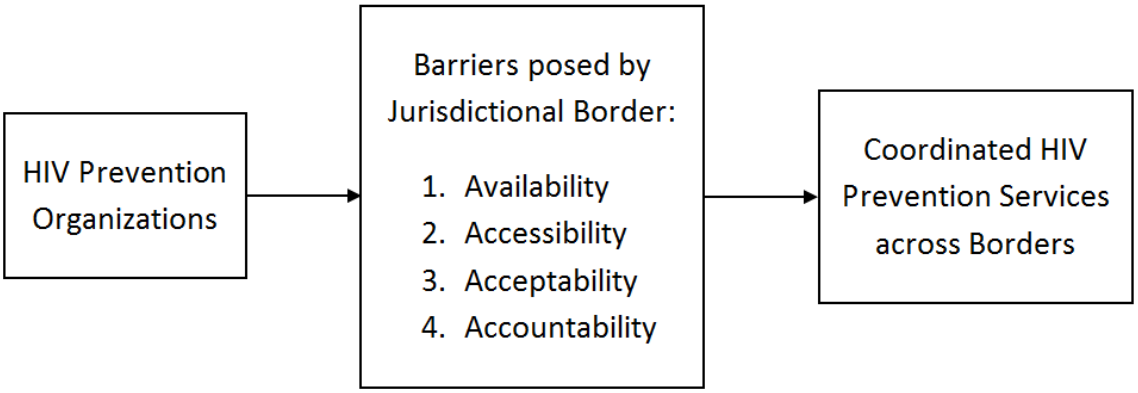
The model used by Zuniga was selected because the four main components of the model seem reflective of what was identified in the border theory literature and in literature on coordinated HIV prevention and treatment (i.e., cultural, political, and economic differences across borders; access to services that are affordable and acceptable). Therefore, for the purpose of this research, the following theoretical model of healthcare service delivery will be examined in the Washington, D.C. - Maryland border region.

1.3 Overall Conceptual Framework

Figure 1.3 below shows the Conceptual Framework for this study. There are four main components of the framework: 1) HIV Prevention Organizations, 2) Barriers posed by jurisdictional border, 3) the four components of the Health Service Utilization Model, and 4) HIV Prevention. The unit of analysis for the study is *HIV Prevention Organizations*. HIV Prevention Organization is defined as an organization that provides HIV prevention services (i.e. condom distribution, education, counseling, testing, and referral) to residents living in the high-morbidity, urban-suburban border region. When

HIV Prevention Organizations, are frequented by individuals residing in two different jurisdictions, they may require relationships with other organizations involved in HIV prevention on each side of the jurisdictional border. The second component of the model is Barriers posed by Jurisdictional Border. For the purposes of this study, a jurisdictional border is defined as a man-made border demarcated for political purposes (e.g., between two states). A jurisdictional border may be used to contain policy governing practice in a specific region, where policy applies to populations residing in that region. The four constructs in the model under Barriers Posed by Jurisdictional Border make the framework for exploring barriers posed by a jurisdictional border. These four constructs are defined above in section 1.2.2 in the discussion of border theory. The last component of the framework is HIV prevention. HIV Prevention is defined as evidence-based activities which can reduce the risk of new HIV infections. Specifically, these activities include: abstinence and comprehensive sexual education, condom distribution, advocacy and outreach, and STD and HIV testing, promotion of PEP and PrEP, and activities that increase treatment engagement of PLWH.

Figure 1.3: Conceptual Framework: System Barriers to HIV prevention and Treatment posed by Jurisdictional Border



1.4 Study Goal, Research Question, and Specific Aims

The goal of this research is to develop a model of organizational barriers to coordination of HIV prevention across jurisdictional borders.

This study will:

1. Examine stakeholder perceptions of HIV prevention challenges, and the extent to which there are disconnects between the services available to vulnerable populations. [manuscript 1]
2. Describe collaboration between HIV Prevention Organizations (HPOs) and correlates of collaboration across a jurisdictional border. [manuscript 2]
3. Determine whether the MMLR further defines, operationalizes, and validates the Health Services Research Utilization Model as a comprehensive and useful model to examine and explain organizational barriers to coordinated HIV prevention across jurisdictional borders. [manuscript 3]

1.5 Definition of Key Variables

HIV Prevention Stakeholders. Stakeholder Theory postulates that a stakeholder is any person or entity who has a stake or who may be influenced by the outcome or project of interest (Tullberg 2013). For the purposes of this study, an HIV Prevention

Stakeholder is any person or entity who has the ability to impact HIV prevention services, activities, or funding for such activities, and those who are recipients of those funds and/or services. Therefore, HIV Prevention Stakeholders include federal and local funding agencies, state and local health departments, medical professionals, community-based organizations, and community residents residing in high HIV incidence regions.

1.6 Significance of Research and Public Health Implications

1.6.1 Public Health Implications

Healthcare access challenges for those with HIV/AIDS have enlightened us to challenges with the conventional health care system. Strained resources require innovative thinking about how to address challenges posed by the healthcare system. Identifying new solutions to these health system challenges for HIV may change the way we think of healthcare and provide solutions to other public health access challenges. The results of this research may identify the need for system-level interventions to adequately address the HIV epidemic in the United States.

1.6.2 Affordable Care Act

Since the Supreme Court decided that mandatory Medicaid expansion was unconstitutional, states have the option of implementing Medicaid expansion and then eliminating expansion at a later point in time. These state-level differences in Medicaid coverage may create differences in coverage on each side of a state border, resulting in cross- jurisdictional healthcare, or movement of the Medicaid population as coverage changes. In the DC Metropolitan region, as of February 2013, bordering states already

differ in their participation in ACA; Washington, D.C. has completed Medicaid expansion and established a Health Benefit Exchange, while Maryland is still only in the planning phases (Emily Gantz McKay, February 2013, "Implementation of the Affordable Care Act and its Implications for HIV/AIDS: National Issues & Regional Status. EGM Consulting, LLC, Bazilio Cobb Associates).

This research will culminate in a list of organizational barriers to coordinated HIV prevention across jurisdictional borders. This list can be used to: 1) assess reasons for lack of coordination across jurisdictional borders, and 2) evaluate reasons for lack of coordination across jurisdictional borders.

1.7 Summary

This study will define barriers to coordinated HIV prevention and treatment across a jurisdictional border, describe how these barriers are currently navigated by stakeholders, at the organizational level, and provide recommendations for new ways of addressing these barriers. This project could have implications for the functioning of community based organizations including funders, health care service providers, governments, non-profits, and businesses.

My primarily responsibility was to ensure that the data collection occurred, planning logistics of focus groups and interviews, recruiting participants, getting data collection instruments IRB approved, and making sure we had enough staff and appropriate equipment for all activities. My experience and training with Dr. Boekeloo conducting focus groups on an NIAAA grant addressing college drinking behaviors prepared me for data collection activities for this dissertation.

Though it may be difficult for me to remain completely objective, because I am starting with some preconceived notions from interacting regularly with HIV stakeholders and community members in the study population, this community participation will likely improve the significance and usefulness of the findings. My relationship with this community and my history of working towards system-level change in this community will increase my ability to be objective in my analysis of the Health Service Utilization Model as a framework for understanding and addressing jurisdictional barriers to coordinated HIV prevention efforts. If the model is truly a good fit, then it will benefit the community. If the model is not a good fit, this is also important to understand so as not to steer stakeholders and community members down a path that will not be fruitful.

The results of this study may be generalizable to HIV epidemics spanning international borders, as well as domestic borders. There are other areas in the U.S. experiencing an HIV epidemic as well as resource disparity across metropolitan jurisdictional borders. There are currently 53 recipients of Ryan White Care Act Part A funding to "Hard Hit Urban Areas." These regions often cross jurisdictional borders, requiring the need for collaboration and coordination between entities involved in HIV prevention efforts (Ryan White Target Center website https://careacttarget.org/grants/58). Some of these regions also cross state borders, such as the New York MSA (i.e., NY, NJ, and PA), the Chicago MSA (i.e., IL, IN, and WI), and the Philadelphia MSA (i.e., PA, NJ, DE, MD).

While challenges related to collaboration for HIV prevention are not unique to the case study area, there are some characteristics of the case study region which may make it

unique. In the state of Maryland, the geographic location of the state health department is in Baltimore City, which is experiencing an HIV epidemic and has its own unique challenges to HIV prevention. The case study region borders the District of Columbia, the city (district) with the largest HIV epidemic in the country. Because the case study region is between two major HIV epidemics, but is located outside of the jurisdiction border of these epicenters, responsibility for the case study region is often unclear between political leaders. The case study region is in the state of Maryland; however its population tends to migrate the porous border between Washington, D.C. and the state of Maryland. Still, transient and migratory populations are challenges to HIV prevention across the world (MacPherson, Douglas and Gushlak, 2011; Soskolne and Shtarkshall, 2002; Sangaramoorthy, 2008; Miller-Thayler, 2010).

Chapter 2 Review of the Literature

2.1 The importance of studying HIV in the study region and global implications of the study

2.1.1 Global epidemic, domestic challenges

HIV is a global epidemic; however the work necessary to curb rates of new infections and eradicate the virus requires domestic, as well as international attention. Washington, D.C. and its suburbs share one of the largest HIV epidemics in the United States. Among metropolitan areas in the United States, this region ranked fourth (behind NY, LA and Miami) in new cases of HIV diagnoses in 2011; that is 1,969 newly diagnosed cases of HIV in Washington, D.C. and bordering counties in Maryland, Virginia and West Virginia (CDC HIV Surveillance Report, 2011. Vol. 23, Table 23). In 2011, Maryland had the highest rate of new HIV diagnoses of all states, 30.6 new diagnoses per 100,000, and ranked third among states and territories surpassed by the U.S. Virgin Islands (33.0 per 100,000) and the District of Columbia (155.6 per 100,000) (CDC HIV Surveillance Report, 2011. Vol. 23, Table 19). It is notable that the District of Columbia, having the highest rate of new HIV diagnoses in the nation, shares approximately two thirds of its jurisdictional border with the state of Maryland.

2.1.2 Need for strengthening HIV prevention and treatment infrastructure

Over the last three decades, the HIV epidemic has created the impetus for the formation of organizations – often grassroots and community-based – to address the needs of people living with HIV (PLWH) and prevent the on-going spread of the epidemic. These organizations include public agencies, clinics, faith-based organizations

and grassroots non-profits; many of whom focus their efforts on high-risk groups facing social injustices. More of these resources or "HIV Prevention Organizations (HPOs)" formed in urban areas, where the HIV epidemic originated in the United States. However in recent years, the HIV epidemic has spread into suburban and rural neighborhoods; the Washington D.C. metropolitan area provides an example of this cross-jurisdictional spread of the HIV epidemic (DeRenzis & Rivlin, 2007; Allard & Roth, 2010; Wallace & Wallace, 1995). Movement of the HIV epidemic from urban to suburban areas occurred as the urgency surrounding HIV/AIDS has dissipated and deaths from AIDS waned to historic lows. The unfortunate consequence of this good news is that this movement of the epidemic into the suburbs has been relatively silent and grassroots efforts or expansion of existing HPOs has been limited or minimal.

At the 2012 International AIDS Conference, Health and Human Services Secretary Sebelius stated the following:

> *"We are reminded over and over again that we need a collective response to turn the tide against HIV/AIDS. That's why we're making a new effort to reach out to community-based organizations, businesses, foundations, non-governmental organizations, faith-based organizations and other partners to ask how we can work together. These public-private partnerships will help make a difference in people's lives."*

This statement from Secretary Sebelius aptly describes some of the greatest challenges in the ongoing battle to end HIV/AIDS. Defeating HIV/AIDS requires a systematic

approach, coordinating activities and relationships between multiple levels in the health system and community as well as multiple partners at each level of the system. When all entities in the system are functioning together, individuals requiring HIV prevention and care services will have the best opportunities for preventing and/or treating HIV/AIDS.

A recent article in the Washington Post reported on the results of the nation's first-ever standardized test on health and sexual education (Brown, 2012). In the spring of 2012, more than 11,000 students in the D.C. Public School System participated in a 50-question exam on health, administered by the Office of the State Superintendent of Education (OSSE). While 75% of students were well-informed about questions related to the biology of sexuality and reproduction, only 46% were able to locate health resources, defined as information and assistance (Brown, 2012). If individuals at risk for HIV are unable to locate information and assistance for sexual health concerns, this access barrier makes it less likely that they will obtain the resources they need; thus putting them at a greater health risk. This is where the actions and behaviors of organizations can have an indirect impact on HIV infection rates.

2.2 The Social Ecological Model

The epidemiologic shift in leading causes of death and morbidity from infectious disease to chronic diseases related to lifestyle has led to beliefs that negative health outcomes and illness are the fault of the individual. In the past, this notion has led to insurance companies dropping coverage for conditions defined as "personal lifestyle decisions," as early as 1988 (New York Times). Even among the scientific community, behavior change interventions focused on the individual have predominated, often at the

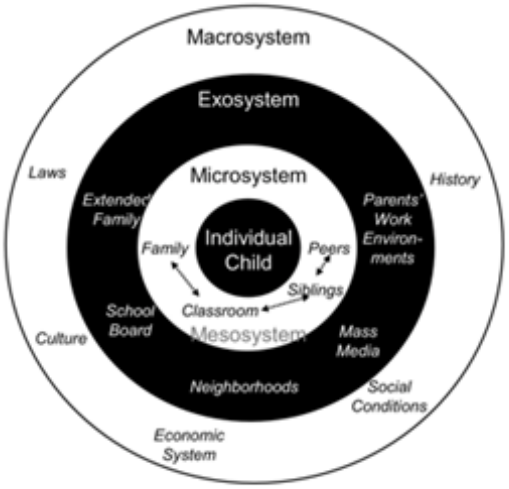
expense of interventions needed in the physical and social environment. There are three possible explanations for this focus on the individual. First, the field of health promotion emerged out of social psychology, which is a field dominated by theory about individual behavior. Another possibility is that a basic challenge of systems theory is that implementing systems change in a democratic system where society has conflicting values can be very difficult. Finally, interventions focused on the individual are easier to evaluate in the short-term, compared to the cost and complexity of evaluating a systems intervention. This challenge was stated eloquently by McLeroy, Bibeau, Steckler and Glanz as: "*emphasis on only the individual behavior instructs people to be individually responsible at a time when they are becoming less capable as individuals of controlling their total health environment (1988).*" This point is very important, and is especially true with regards to HIV and HIV prevention. While individual behavior is an important predictor of HIV infection, there is evidence that social and physical elements in the environment, inefficient policies, culture, poverty and access to resources are also factors influencing HIV incidence and prevalence rates not only in the United States, but all around the world. The following section will discuss the theoretical evolution of the Social Ecological Model, beginning with early ecological theory.

2.2.1 Ecological Theories

The Ecological Framework states that health is influenced by multiple factors of the physical and socio-cultural environment, that these multiple factors and the environment interact, and that prevention is most effective when coordinated across levels (individual level, interpersonal level, institutional level, community level, and policy); (McQuiston, Choi-Hevel, & Clawson, 2001). As described by McLeroy and

colleagues, (1988) central to the ecological perspective is the idea of the interaction between the individual with his or her social and physical environment. Ecological theories have been discussed and applied to address public health challenges since the late 1970s. Ecological models divide influences on a health problem into different levels. These levels can be beneficial in constructing plans for intervention and analysis of health outcomes impacted by environmental and social influences, in addition to personal influences on behavior. Most recognized as the father of the ecological approach in health promotion and health education is Urie Bronfenbrenner, who viewed behavior as being affected by multiple levels of influence. His ecological model (*see Figure 2.1*) consists of four environmental influences on behavior: the microsystem, the mesosystem, the exosystem and the macrosystem.

Figure 2.1: Bronfenbrenner's original model



The concept of looking at an entire social and environmental system, plus the interactions between each level of this system revolutionized thinking about health behavior. It is important to consider that in developing this model, Bronfenbrenner was focused on child development and how these different levels of influence affected the health behavior of a child as it entered adolescence. These levels may be very appropriate in that specific context, as well as in other similar contexts; however, the model as it was initially created is not exactly the best fit for all health behaviors.

Consequently, there have been many adaptations of this model since its inception in 1979. Bronfenbrenner's theory of environmental levels of influence on behavior has been adapted by nearly all areas of public health. This study aims to explore the influences of organizations and borders on HIV prevention. Bronfenbrenner's original model lacks necessary specificity accomplish this aim, therefore it will be adapted, as it has by other scholars in public health. In Bronfenbrenner's microsystem, he refers to the interrelations among an individual's immediate environment (e.g. interrelation between family, school, peers, and church). Bronfenbrenner's macrosystem is defined by culture and values, which are considered to be the outer-most level of the model. In the hypothesized model for this study, the community level is where culture and values come into play, and it is not as far removed from the individual in the model, with two other levels more distal to the community level. The culture and values that influence an individual are a function of the person's place in the physical and social environment, which occur at the community level. Community representatives' perspectives will be analyzed in this study. Also, those working at community-based organizations, in the next layer of Bronfenbrenner's model, often represent the community. The exosystem of Bronfenbrenner's model includes organizations – HIV prevention organizations for the purposes of this study. As theorized by Bronfenbrenner, these organizations must regularly interact with the most distal layer of the model, the macrosystem. This interaction between the exosystem and the macrosystem will be a focus of this study. Organization and government relationships are further removed from the individual, as are policy influences in Bronfenbrenner's theoretical model. Still, these relationships have an impact on the individual, and all system levels in-between.

Finally, another major tenant of Bronfenbrenner's model, as well as Albert Bandura's Social Cognitive Theory which preceded Bronfenbrenner, is the concept of reciprocal causation between the individual and the environment. I will argue that what we see in terms of influence on health behavior – especially sexual health risk and treatment behavior is not necessarily reciprocal causation between the individual and the environment. Interaction between the individual and the environment may be a factor influencing behavior, but to say there is causation is an oversimplification of the complexity of human behavior. For example, if environment caused individual behaviors, then everyone in the same environment would have the exact same health behaviors; and we know this is not the case. Still, it is very likely that individual's interactions with others at each level of their social and physical environment, as well as the broader political infrastructure pose certain facilitators and barriers to health behaviors, thus influencing individual health behavior.

The other side of reciprocal determinism implies that the individual impacts their environment. How this occurs in terms of HIV prevention is difficult to understand. For example, if there are few testing resources - a physical element of an individual's environment – there is not a lot that one individual can do the change that structural aspect of their environment. However, an individual may be able to impact those immediately around them, such as family and friends. They may also be able to impact their local community. In terms of impacting organizations and policy, change at this level is more likely to occur with the cumulative actions of multiple people, making it unlikely that an individual can cause influence these levels as much as these levels impact the individual.

The variation of Bronfenbrenner's model is what will be used to construct the theoretical framework to assess benefits and barriers of borders in HIV prevention and treatment. McLeroy, Bibeau, Steckler and Glanz developed an ecological model loosely based on Bronfenbrenner's model. In their model, behavior is determined by intrapersonal, interpersonal, institutional, community and policy factors.

McLeroy et al. model differs from the conceptual framework for this study in the labeling and definitions of institutional and community levels. One difference between the model for this study and the McLeroy model is their placement of institutional factors in the model. McLeroy and colleagues define institutional factors as social institutions with organizational characteristics and formal and informal rules about operation. Community factors are defined as relationships among organizations, institutions, and informal networks with defined boundaries. For this study, we will define community as the physical and social elements in an individual's environment, which are bound by geography and shared history. Due to this definition, interaction between community and individual is likely more frequent than the institutional level as defined by McLeroy. Similar to McLeroy's 'institutional level, this study will have an organizational level that is one level higher than he community level, and one level below the policy level. The organization level is similar to the definition of McLeroy's institutional level; however, in this study, we know that our impacted community is closer and has more frequent interaction with the elements in the community than the organizations that provide HIV prevention services. If they had more interaction with these organizations, it would be less likely that adherence to care and HIV case findings would be the major challenges to prevention that we know they are.

2.2.2 Application of Ecological Theories: Organization-level health programs and interventions

There is a growing recognition that most public health challenges (e.g. encouraging people to exercise regularly, improve their diet, and refrain from smoking) are too complex to be understood adequately from single levels of analysis and, instead, require more comprehensive approaches that integrate psychological, organizational, cultural, community planning, and regulatory perspectives (Stokols, 1996).

Studies have shown that multilevel interventions which address social determinants of health at a number of levels can mutually reinforce one another to produce longer and more sustained effects than interventions that target only one level (Weiner, Lewis, Clauser, Stitzenberg, 2012; Stokols, 1996). Dr. Meghan Lewis's research uses a causal modeling framework to describe five strategies for increasing potential complementarity or synergy among interventions that operate at different levels of influence. These five strategies are: accumulation, amplification, facilitation, cascade, and convergence. Given this specific challenge of addressing HIV prevention and treatment, the approach of utilizing the social ecological model to examine borders is appropriate. In addition, based on recent findings, we know that stakeholders can speak to specific opportunities and challenges presented by these jurisdictional borders. For the purposes of this study, the *organization level* will be defined as the relationships between organizations involved in HIV prevention and treatment on each side of the jurisdictional border. Interaction between community residents with these organizations and impact of the border and cross- jurisdictional organizational relationships will also be explored.

Organizations are at the meso-layer of the model Social Ecological Model. They are impacted by the community level as well as the policy level. Since the goal is to improve collaboration and coordination between organizations and agencies who have the potential to or currently provide HIV Prevention services, this requires attention to how organizations work together with other agencies as well as how they are serving the population.

2.2.3 Case Study Application: Washington, D.C. and Maryland public health infrastructure

The HIV/AIDS Prevention and treatment infrastructure for Washington, D.C. is best described in the D.C. Comprehensive HIV Prevention Plan – the latest version is for the years 2012-2015. There are 11 goals of the plan, which are consistent with the National HIV/AIDS Strategy. These goals are: 1) Increase the number of HIV positive persons who know their status, 2) Provide prevention interventions for HIV-positive individuals, 3) link HIV-positive individuals to care, 4) Reduce risk behaviors by high-risk negatives, 5) Facilitate voluntary testing for other STDs, 6) Increase and expand the distribution of condoms to HIV positive individuals, high-risk negatives, and the general population, 7) Provider Partner Services for HIV positive persons and their partners, 8) Prevent perinatal transmission of HIV, 9) Continue and expand Social Marketing campaigns to support prevention initiatives for PLWH and high-risk negatives, 10) Establish non-occupational post exposure prophylaxis (NPREP) and Pre-Exposure Prophylaxis (PrEP) policies and protocols for the District of Columbia, and 11) Engage community stakeholders in HIV prevention planning (Washington, D.C. Department of Health).

Because the HIV epidemic is not bound by borders, the Washington D.C. Regional Eligible Metropolitan Area has a 2012-2014 Comprehensive HIV Care plan, which is intended for use by organizations, agencies, and all entities receiving federal funding for HIV Care through the Ryan White Care Act. This plan is supported by the Washington, D.C. Mayor and Director of the D.C. Department of Health, the Director of Human Services at the Northern Virginia Regional Commission, and the Health Officer/Director of the Prince George's County, Maryland Health Department. The main components of the plan address healthcare reform, the National HIV/AIDS Strategy goals and objectives, treatment as prevention, unmet need of PLWH who leave care, evaluation through use of the treatment cascade measures, and considers jurisdictional differences and a commitment to parity in access to all PLWH in the region (Metropolitan Washington Regional Ryan White Planning Council, 2012).

Though the Comprehensive Care Plan for the Washington, D.C. EMA includes consideration of its neighboring suburb, Prince George's County, Maryland, the State of Maryland also has its own HIV Plan, which incorporates a comprehensive HIV plan, a statewide statement of need, and an HIV prevention plan. The goals of the Maryland HIV Care Plan include: 1) Routine screening in clinical settings, 2) Targeted HIV testing in non-clinical settings, 3) Initial and ongoing HIV/STI partner services, 4) Ensuring people who are newly diagnosed and those not in care enter care by collaborating with HIV testing and linkage to care programs and facilitating connections to support services, 5) Improve health outcomes by ensuring access to care, 6) Expand risk assessment and risk reduction interventions for PLWH with HIV care providers, 7) Increase condom distribution and social marketing/education efforts, 8) Increase HIV testing and risk

reduction interventions with HIV negative populations, 9) Decrease the number of pediatric HIV cases, 10) System-wide coordination of HIV prevention and care services, 10) reduce disparities in access and services among affected subpopulations and historically underserved communities (Maryland Department of Health & Mental Hygiene, 2012).

In Prince George's County, the region bordering Washington, D.C. and sharing its HIV epidemic, the counties response to HIV/AIDS is guided by several additional documents, including the Prince George's County Health Improvement Plan (Creekmur & Preneta 2012). The Prince George's County Health Improvement Plan considers the results of county needs assessments and feedback from community residents and stakeholders to develop, monitor, and evaluate a strategic plan for the county. Six priority areas were developed for the 2012-2014 plan: 1) Ensure that Prince George's County residents receive the health care they need, particularly in low income, uninsured and underinsured adults and children, 2) Prevent and control chronic disease, 3) Improve reproductive health care and birth outcomes for women in Prince George's County, particularly among African American women, 4) Prevent and control infectious disease, 5) Ensure that Prince George's County physical environments are safe and support health, particularly in at-risk communities, 6) Ensure that Prince George's County social environments are safe and support health. In priority number 4, "Prevent and control infectious disease" county employees, community stakeholders, and community volunteers have focused major efforts on addressing high rates of HIV and STDs through the work of the Prince George's County Health Action Coalition. Activities have included the development, implementation, and evaluation of an HIV awareness

campaign, special training sessions for healthcare providers on HIV counseling and testing policy and federal recommendations, and a 2-day community forum where community residents heard about HIV and stigma from community leaders and academics. All of these activities of the Prince George's County Health Action Coalition are conducted by the effort of volunteers. While volunteer efforts are not to be unappreciated, when an infectious disease reaches prevalence rates nearing epidemic proportions, solutions cannot be reached without financial resources. Unfortunately, as stated in the Prince George's County Health Improvement Plan,

> *"Unlike neighboring jurisdictions, our County's ability to generate revenue to provide public services is severely restricted because of a 1978 amendment to the County Charter called TRIM (Tax Reform Initiative by Marylanders) that places a cap on the collection of real property taxes. Our current assessable tax base, especially with regard to commercial properties, is insufficient to address all of the County's needs," (*Creekmur & Preneta 2012).

As is apparent from the above descriptions, the Washington, D.C. metropolitan region is impacted by an HIV epidemic; however, each jurisdiction included in the region (i.e. the District of Columbia, Suburban Maryland, and Northern Virginia) is guided by its own unique infrastructure, policies and resources. These jurisdictions do not share the same eligibility requirements for PLWH, provide the same services, or allocate funds in the same way. This makes the public health systems response to the HIV epidemic in the

region increasingly difficult. Fortunately, there are a few key initiatives, which have gained momentum in recent years that work to address cross-jurisdictional planning in the region. These are the Metropolitan Washington Regional Ryan White Planning Council, The Washington EMA Quality Management Cross-Part Collaborative, and the Washington, AIDS Partnership. The **Metropolitan Washington Regional Ryan White Planning Council** sets eligibility for services and provides operational standards for HIV care. The group is working to address cross-jurisdictional differences. One recent accomplishment was providing funds for regional support groups, which are not dependent on residency. **The Washington EMA Quality Management Cross-Part Collaborative** is an initiative which began in January 2011 to improve quality of Ryan White services and grantees by strengthening consumer involvement, conducting trainings, planning sessions, and working collaboratively. The Collaborative was founded by the HIV/AIDS Bureau and National Quality Center (NQC) through an initiative to improve HIV/AIDS care across the region. **The Washington AIDS Partnership** is the largest private funder of HIV prevention, education, and advocacy in the region. The Partnership is a collaboration of local grant making organizations and individuals which has been very active in the region for over 20 years. While not specifically focused on HIV, the **Sexually Transmitted Infections Community Coalition** (STICC) serves as an opportunity for those working on STD and HIV prevention in the region to come together to solve regional problems. The mission of STICC is, "*to establish and maintain partnerships that leverage resources to prevent and control sexually transmitted infections, including HIV, in the Washington, DC Metropolitan Area*."

2.3 Theoretical focus on borders and applicability of borders study

According to a logic model developed at the University of Maryland (UMD), School of Public Health prior to the creation of the UMD Prevention Research Center, reaching across borders can reduce health disparities and lead to community empowerment and community enlightenment (Boekeloo, 2009). Interventions to achieve empowerment and enlightenment require identification of border challenges, raising awareness of challenges, and bringing together members of each side of the border for solutions. The purpose of this study is to use theory to describe and understand how borders impact the continued spread of HIV in the area surrounding the Nation's capital. In order to do this, we must examine the existing literature on borders and border theory.

2.3.1 Border Theory

In the conference paper: 'Borderlands studies and Border Theory – Linking Activism and Scholarship for Social Justice,' Nancy A. Naples discusses Border Theory and how it is viewed differently by cultural theorists and social scientists. She begins with a brief history of border theory, and praises the inaugural text, "Borderlands/ La Frontera: The New Mestiza" by Gloria Anzaldua as the most influential of four key theoretical texts which have shaped the field of borderland studies. Gloria Anzaldua's text argues that borders do more than separate geography – they have a sociological and psychological effect on people. According to Naples, the goal of early borderlands study was to understand the complex processes that shaped politics, economics, and culture along the U.S.–Mexico border. Naples contends that one of the challenges to interdisciplinary practice of border theory is the tendency of scholars to adopt frameworks using border theory "*that are out of the context which they were generated*."

However, Vila states that border theory is not only specific to the U.S.–Mexico borderland, but can be applied to any physical or psychic space about which it is possible to address problems of boundaries, including: country borders, ethnic borders within the United States, gender borders, and borders among disciplines (Vila, 2003). Theorists influenced by Anzaldua's borderlands writings, view borderlands as sites that can "*enable those dwelling there to negotiate the contradictions and tensions found in diverse cultural, class, and other forms of difference*." Thus, there is evidence of disagreement on whether border theory can be generalized outside of the U.S.–Mexico border context. One of the main arguments of Naples is that there must be an emphasis on praxis; that is, linking theory with practice in the scholarly expansion of border theory into different disciplines. Early scholars focused on praxis of border studies, specifically: welfare rights, childcare, health, birth control, sterilization, legal rights, prison experience, sex roles, cultural heroes, labor struggles, and organizing. Naples states that praxis is a driving force in contemporary border research projects. Bridging the gap between the activists living in the border struggle, and the academics and researchers studying the border is an important step in building upon existing border theory. Naples explains: "*in bridging the boundary between the community and academia for the purpose of social change, activist scholars argue for the importance of praxis to enhance the links between experience, political struggle, and theoretical analysis*." Community-based participatory research is a process where community are incorporated in all aspects of developing, implementing, and interpreting research; therefore, this may be an appropriate approach for continued study of border theory.

Author of "*Disposable Women and other Myths of Global Capitalism (2006),*" Melissa Wright gives an example of a *Mexicana* on the U.S.–Mexico border who works her way out of her oppressed situation, located within the rules of capitalism, yet also outside of it (Wright, 2006, p.3). This may bear some resemblance to the experience of those in the inner-beltway Prince George's County, who are predominantly African American, living in the wealthiest primarily African American county in the United States. They are surrounded by others who experience racial stigma like them, but have somehow managed to become successful; though success does not necessarily equate with 'privileged.' Wright also explained how women may experience "*gendered and racialized processes that sustain transnational capitalism*." While the focus of this study is not transnational, it is trans-jurisdictional. Thus, it is possible that, similar to these transnational border studies on the U.S.-Mexico border, movement from one geographical location categorized by poverty and oppression to another geographic region will not change privilege if that privilege is based on race or geographic nativity. Anna-Liisa Aunio has a slightly different take on the field of border theory. She acknowledges border theory as a field of research that has been driven by feminist theory, and that this has resulted in a focus on borders navigated by oppressed groups (Aunio, 2009). However, Aunio expands further by recommending that border theorists explore when borders are salient in the everyday lives of both the oppressors and those oppressed by borders. She suggests this may be accomplished through examination of instances of exclusion and resistance, as well as inclusion and acceptance (Aunio, 2009). She poses the question "W*hen do individuals take-up borders in order to create and reinforce privilege*?" This raises an interesting point in this exploration of HIV prevention and

treatment. An examination of differences on each side of the jurisdictional border may reveal privilege on one side of the border, and lack of such privilege on the other side of the border. Differences in privilege in a densely populated metropolitan area can create challenges when rapidly evolving economic conditions cause major shifts population movement across jurisdictional borders.

In 2008, Kathleen Staudt developed a "border-grounded framework" which includes institutional and community actors who align to prevent violence against women along the U.S. – Mexico border (Naples, 2010; Staudt, 2008). Development of this theory included involvement with local activists and an interdisciplinary group of individuals pursuing social justice for women who had been assaulted. Staudt's methods included an iterative process between participant observation, activism, and scientific research. By opening dialogue and activity between scholars and activists, Staudt is credited with developing a new approach that supports a movement towards social justice along the U.S.-Mexico border. This approach bears resemblance to community-based participatory research, which has proven to be equally successful in addressing social justice issues in communities. This study has evolved out of a community-based participatory research process, and will explore how a model of rights-based approach to health captures the barriers to coordinated HIV prevention across jurisdictional borders.

Crossing borders can occur for many reasons. Sociologist Lionel Cantu examines how borders impact sexuality and immigration, raising some interesting thoughts about how borders relate to identity or enables one to escape identity in a particularly social and geographical context (as cited in Naples, 2010). He argues that, "*issues of identity are both shaped by the immigration experience, as well as constitutive of it*." For example, in

response to discrimination or stigma in their own communities due to sexual orientation, one may feel motivated to move across the border to a new, more accepting community. Again, while initially discussed in terms of a conservative Mexico and a more socially liberal U.S. environment, this concept could also apply in terms of urban-suburban borders within the United States, and may therefore apply to the specific jurisdictional border examined in this study. Cantu continues to point out (as cited in Naples, 2010) that sexuality could also influence relationships formed among individuals in different communities, bounded by borders. Lastly, he argues that sexual identity can be reshaped through the process of migration across borders, by enabling practices and behaviors not previously possible.

2.3.2 Borders, Health and Health services

A questionnaire by the Istituto di Sociologia Internazionale di Gorizia (ISIG) in 2009 examined national borders in the Mediterranean and their impact on health systems. They determined that borders change from hard to soft. Cooperative social actions are key for a positive re-definition of borders (when they become too hard or too soft). Health system variables, such as efficiency and effectiveness and functioning are altered by borders because of: 1) gains on one side of the border not available on the other side, 2) quality of public health services may be worsened by the failure of national health systems to overcome borders in organizational terms, 3) border-based discriminatory practices may be implicitly accepted out of consolidated unilateral interpretations of identity (ISIG 2009). In the same year, another study conducted in the countries around the Mediterranean Sea was published that examines the effect of a communication network for disease control on overcoming barriers posed by jurisdictional border. The

system shares epidemiological characteristics and public health problems. In 2006 the EpiSouth Project was started as a framework for collaboration for communicable diseases surveillance and training in the Mediterranean Basin. Overall the network succeeded in creating cohesion, mutual trust and concrete collaboration on cross- jurisdictional public health issues in a geographical area that is not addressed as a whole by any other initiative or organization (Dente MG et al, 2009). Similarly, the European Observatory on Health Systems and Policies Analysis of different dimensions that determine the scope and policy of cross- jurisdictional care: access to healthcare, benefits and tariffs, quality and safety, patients' rights, cross- jurisdictional collaboration and cross- jurisdictional health care data (European Observatory on Health Systems and Policies). A study looking at collaboration between health services across Mediterranean country lines looked to mobile healthcare as a solution. Using telemedicine, hospitals can offer medical services in "wide teams" which was not previously possible due to geographic restrictions. Expected outcomes of telemedicine: 1) overcome geographic restrictions 2) improve quality of services provided 3) reduce costs of resources 4) reduce patient expenses 5) reduce time and costs of hospitalization 6) creation of a medical database, allowing comparative studies and statistical analysis (Spyrou, et al., 2008).

Studies of the U.S. Mexican border have identified transnationalism as a challenge in addressing infectious disease outbreaks. It was in this U.S. – Mexico border region that public health first recognized that infectious diseases could not be addressed in this migrant population without treating populations on both sides of the jurisdictional border. Most of these studies are examine aspects of health of a population across international borders. For example, one study of HIV/AIDS patients residing within two

miles of the U.S. Mexico border (i.e., on each side) identified challenges created by the border in four categories of service utilization: availability, accessibility, acceptability, and accountability (Zuniga, Organista, Scolari, Olshefsky, Schulhof, & Colon, 2006), based on the Behavioral Model of Health Service Utilization (Aday, 1995 in Zuniga, et al., 2010). While international borders pose different challenges than domestic borders, theoretical concepts and lessons learned from studies of international borders and health may be applied to domestic border health issues.

In 2006, National and Cross- jurisdictional health issues were evaluated in the European Union through a project called, HealthACCESS (Busse, Worz, Foubister, Mossialos, & Berman, 2006). There were 132 cross- jurisdictional arrangements identified in the 10 European countries involved in the study; however, these arrangements were all concentrated in a few countries. Cross- jurisdictional arrangements defined as having the goal of facilitating cross- jurisdictional access to health services, and predominantly, but not exclusively, based on formal agreements between collaborators. These arrangements do not include movement of individual patients, movement of health professionals, or any kind of arrangement which did not have improved access as its goal. HealthACCESS identified several different types of cross- jurisdictional arrangements that could promote improved access to healthcare. These arrangements are: insurer-provider, provider-provider, emergency services, intergovernmental cooperation, health insurance card projects, and support/advice. The project concluded that there were geographical barriers to accessing health services, as well as organizational barriers to accessing health services. HealthACCESS defined six predominant hurdles to access to health care services. These six hurdles are: 1) the

proportion of the population covered for health care, 2) benefits covered by health care systems, 3) cost-sharing arrangements, 4) geographical barriers to access, 5) organizational barriers to access, and 6) utilization of accessible services. The first barrier (or hurdle), proportion of the population covered, relates to the percent of the population covered by private versus public insurance. The study notes that while the majority has some form of public insurance, private insurance often complements public insurance to cover costs of care which cannot be covered by the public insurance system. The challenge here is that there are some who are not covered by insurance, despite the "universal coverage" available in the EU, and the meaning of health insurance coverage varies in each country in the EU. This can create challenges to cross- jurisdictional collaboration for health services. The second barrier is very similar to the first, but refers to the specific benefits covered versus not covered in the different public insurance systems. The third hurdle is cost-sharing arrangements. While cost-sharing typically does not impede access to care within a country, differing rules and policies regarding exemptions for cost-sharing create difficulty in navigating cross- jurisdictional arrangements. The fourth hurdle identified by the study is geographic barriers to access. This includes the remoteness of an area, the density of providers, and the closeness of a national border. While our case study population is not crossing an international border, closeness to a border, density of providers, and remoteness of an area could all be potential barriers to coordinated HIV prevention in the Washington, Metropolitan region. The fifth barrier to cross- jurisdictional arrangements is organizational barriers to access. Organizational barriers to access include waiting lists, waiting times. These waiting times have been shown to be related to the way organizations operate. Most notable is

that providers working in both the public and private system can be compensated more for spending more time in the private system than in the public system; in some cases this is due to "*brown envelope payments*." The last barrier identified is utilization of accessible services. This is the effect of socioeconomic and demographic variables on access.

One of the other healthcare challenges created by borders has been discussed in 2001 study by MacPherson and Gushulak. They studied the inability to detect and contain imported disease threats at national borders, and called for a new paradigm to facilitate the development of policies and programs to address health consequences of population mobility. Movement of people from epidemic to non-epidemic areas introduces disease to disease-naïve populations (MacPherson & Gushulak, 2011). Populations that come to the U.S. for economic opportunities often end up displaced and vulnerable. They also are at greater risk for adverse health outcomes. The distribution of TB and HIV with social disparities and access to care is an example of this phenomenon. Moya, Loza, and Lusk have described social determinants and health outcomes prevalent along a border region, as well as appropriate structural interventions and policy recommendations for improving health in the region (Moya, Loza, and Lusk, 2012).

It is clear from the literature above that border theory and the impact of borders on population health have been explored in the peer reviewed literature; however, there is still a lot more to learn about the impact of borders on health services.

2.3.3 Borders and HIV

HIV prevention research's insufficient attention to structural influences on behavior has hampered efforts towards ending the HIV epidemic (Latkin, Weeks,

Glasman, Galletly, & Albarrrcin, 2010). Poverty, stigma, and lack of services are structural factors that impeded individuals from protecting themselves from HIV infection. Movement of populations even forces some into behaviors making them at risk for HIV. Models for HIV related behaviors include structural dimensions such as resources, science and technology, formal social control, informal social influences and control, social interconnectedness, and settings (Latkin, Weeks, Glasman, Galletly, & Albarrrcin, 2010). These six dimensions were conceptualized into macro, meso, and micro levels, according to the social ecological model discussed previously in this chapter. Latkin and colleagues describe interconnectedness and dynamic processes of change among these social system components, specifically as they relate to change in HIV testing and safer injection facilities (Latkin, Weeks, Glasman, Galletly, & Albarrrcin, 2010).

In 2002, Soskolne and Shtarkshall developed a framework relating population migration and HIV infections, in order to improve HIV prevention efforts of organizations working with migrant populations. They hypothesized the following model: migration leads to SES and power inequalities, which thus limit social capital; bi-directional interactions of cultural norms lead to loss of culture, migration stress, and depleted psychosocial resources; depleted psychosocial resources and limited social capital lead to low use of HIV prevention care and services, elevated risk behaviors, and finally, HIV infections (Soskolne & Shtarkshall, 2002). This framework emphasizes that migration alone is not the predictor of HIV infection, but the environmental and psychological stressors that often accompany migration can make migrants more vulnerable to HIV infection than other populations. More recently, Jamaal Marshall

completed a dissertation which analyzed geographic data to determine HIV risk behavior. Results indicate the participants in high-risk zip codes were at higher risk for HIV infection AND having three or more sexual contacts in the six months prior to the interview. He concluded that further analysis of geographic distance and partner selection is warranted (Marshall, J 2012).

In Prince George's County, one example of how jurisdictional border impacts HIV is the distribution of federal funds under the Ryan White Care Act. Currently, Prince George's County receives Ryan White funds for its HIV positive population through Washington, D.C. If Prince George's County applied for status as a Transitional Grant Area (TGA), they can apply for funds separately from D.C. In order to be eligible for TGA status, an area must have reported 1,000 – 1,999 new AIDS cases in the most recent 5 years and have a population of at least 50,000 persons (HRSA).

2.4 Collaboration across jurisdictional borders

Geography can be a barrier to collaboration, because greater distance between collaborators can cause increases in work cost, coordination difficulties, and also limited social ties (Boh, Ren, Kiesler, & Bussjaeger, 2007). Fostering a collegial social environment is also difficult with distance collaborations. For example, spontaneous informal talk can often help move projects forward; however few of those opportunities exist when collaborators are separated by long distances, or different jurisdictions. Building common ground, maintaining awareness, focusing on the project, adjusting when surprises arise are all examples of struggles that are greater in distance collaborations. Boh, Ren, Kiesler, and Bussjaeger suggest that new theoretical arguments are needed to predict how to resolve dilemmas of distance collaborations (2007) and

propose that organizational collaboration across geographic borders may require increased social networking, social ties, and technology solutions).

An environmental scan was conducted to strengthen America's public health system (Libbey & Miyahara, 2011). To understand issues involved in creating formal collaborative relationships between local health departments in different communities. What factors contribute to or detract from the success of these cross-jurisdictional relationships? How are relationships defined by stakeholders?

The goal of the 12 Cities Project is to challenge HHS to better coordinate planning, implementation, delivery and evaluation of HIV/AIDS services in each of these 12 jurisdictions. Specific actions include 1) mapping resources in each jurisdiction, including Ryan White services, community health centers, CDC prevention activities, SAMHSA grantees and Center for AIDS Research activities, 2) share data and information from grantees in each jurisdiction to better-inform locally coordinated planning for prevention, care and treatment, 3) promote opportunities to blend services and – where appropriate – funding streams across Federal programs.

2.4.1 Collaboration as a public health intervention

Public health delivery systems vary widely in their organization and scope of activity; however, more comprehensive, highly differentiated and highly integrated models of public health are perceived to perform more effectively than other public health system configurations (Mays, Scutchfield, Bhandari, & Smith, 2010). High levels of integration between all components of a comprehensive public health delivery system require high levels of collaboration (CDC, 2009). Collaboration can be defined as any relationship between two entities; however, it may occur at different levels of integration

on a continuum from low integration to high integration (Gajda, 2004). For example, low integration may be simply communicating information or exploring interests, while high levels of integration would be planning to achieve a mutual goal while maintaining separate identities (Gajda, 2004). High integration is categorized by ongoing patterns of interaction. Ongoing interaction between organizations often leads to common understanding and common practice (Lawrence, Hardy & Philips, 2002). Common understanding can foster the kind of change that is often credited to collaborative efforts. Collaboration that is ongoing and highly integrated has the greatest potential to lead to community-wide change (Lawrence, Hardy, & Philips, 2002; CDC, 2009).
According the 2009 CDC White Paper, program collaboration "involves a mutually beneficial and well-funded relationship between two or more programs, organizations, or organizational units to achieve common goals. It involves many aspects of comprehensive program management at state and local levels." The 1994 Core Public Health Functions Steering Committee provides a framework for categorizing collaboration strategies among programs. The White paper provides specific examples of potential collaboration strategies for each program function, along with process measures of the collaborative activity.

As discussed earlier, some regions have sought to overcome challenges related to cross- jurisdictional collaboration by utilizing concepts and systems from telemedicine for public health efforts (Spyrou, Vartzopoulos, Bamidis & Maglaveras, 2008). The study of cross- jurisdictional arrangements for health services in the EU reported additional questions to be answered: Do cross- jurisdictional arrangements increase efficiency of service provision, quality of services, and access? How are the benefits and risks of cross-

jurisdictional arrangements distributed? (Busse, Worz, Foubister, Mossialos, & Berman, 2006).

2.4.2 Collaboration and HIV prevention

In a region experiencing an HIV epidemic, care for those infected, and prevention for those at-risk depends on multiple complex individual, interpersonal, and social factors. Addressing the epidemic requires coordinated effort between various health service organizations and social service organizations.

2.4.3 Collaboration across jurisdictional borders for HIV prevention

Borders create a unique community dynamic, because while a community may share culture, geography, socioeconomic and health status, division by political border may add challenges to successful collaborative efforts.

Though the cross-jurisdictional aspect of some health service organization collaborations for HIV prevention and service have not necessarily been emphasized in the literature as significant aspect of collaborative relationships, these relationships do exist and have been successful, even in the face of some border-related challenges. For example, the Four Corners American Indian Circle of Services Collaborative is a Navajo Nation-wide collaborative across the jurisdictional border between New Mexico and Arizona (Duran, Harrison, Shurley, et al., 2013). The goals of the collaborative were to increase awareness of HIV status through screening, education and testing; to increase number diagnosed receiving culturally appropriate care for infection as well as mental health issues, and to reduce new infections by offering effective risk reduction support to positives (Duran, Harrison, Shurley, et al. 2013).

In 2002, the World Health Organization consulted in Geneva to discuss how partnership work can impact health service delivery and improve prevention, care and treatment of HIV/AIDS. The official report of the meeting identified challenges and opportunities for collaborative interaction and partnership between health services and communities. The report also discussed the need for innovative models of health service delivery, which should include collaboration between community and service providers (WHO, 2003). Three broad categories for strategies to improve HIV prevention, care, and treatment were identified: 1) strengthen capacity of healthcare system to interact with communities, 2) strengthen capacity of communities to interact with health services, 3) strengthen the processes and methods for change. The report concluded that better collaborative interactions between health services and communities were essential to better HIV prevention, care and treatment (WHO, 2003).

The past decade has seen a dramatic increase in studies identifying a link between jurisdictional border and health; however, the majority of the literature focuses on transnational health, specifically the U.S. - Mexico border and Eurasia. Studies on domestic jurisdictional borders and HIV remain scarce.

2.5 Barriers I expect to identify, based on my review of existing theories

As I completed my literature review on theories related to organizational barriers to coordinated HIV prevention across jurisdictional borders, I came across several potential barriers, which I believe may re-surface as I analyze quantitative and qualitative data from HIV prevention stakeholders. For one, I learned through the study of boundary theory that borders can be hard or soft, and that border can change and evolve. The ISIG questionnaire, based on this construct of boundary theory found that health systems can

be affected by borders. **Border-based discrimination and disparity**, identified by ISIG as hindrances on the healthcare systems, may also serve as barriers to organizational collaboration and coordination across jurisdictional borders. The review of the literature on collaboration has also helped to identify potential barriers. For example, the EpiSouth project demonstrated how cross- jurisdictional collaboration can improve public health. Cohesion, mutual trust, and concrete collaboration on specific issues were all addressed to successfully achieve cross- jurisdictional collaboration. Therefore, **lack of cohesion, trust and concrete collaboration on specific issues** may be barriers to coordinated HIV prevention across jurisdictional borders. Sharing of services, another collaboration theory construct, is an indicator of how individual organizations operate as a coordinated system. If lack of sharing is evident, the **reasons for lack of sharing of services and resources** would be barriers to coordinated HIV prevention across borders. Border theory highlights **cultural, economic and social differences** across borders. These differences may be barriers to health system coordination and collaboration across the jurisdictional border.

2.6 Health Services Utilization Model

In a 2010 study to determine whether there were access to care barriers and facilitators specific to the U.S.-Mexico border region, researchers held focus groups at community clinics on each side of the jurisdictional border (Zuniga, Blanco, Palinkas, Strathdee, & Gifford, 2006). Researchers asked participants about four dimensions of human and social service utilization: 1) Availability of services, 2) Accessibility of services, 3) Acceptability of services, and 4) Accountability. These four dimensions have been discussed as dimensions of health service delivery as early as 1985, by Mary E.

Stefl and David C. Prosperi; however, with slight differences from the Zuniga model. Blank, Fox, Hargrove and Turner came up with the exact same four dimensions as obstacles to effective mental health service delivery in rural areas (1995). In the year 2000, the United Nations Committee on Economic, Social, and Cultural Rights adopted a General Comment on the Right to Health, which proclaimed that the right to health contains four elements: availability, accessibility, acceptability, and quality of services (United Nations Economic and Social Council, Committee on Economic, Social, and Cultural Rights, 2000). The General Comment (General Comment No. 14) states that these four elements are the underlying determinants of health, which should be assured to all people. This decision by the United Nations was part of a new rights-based approach to health policies and programs. More recently, in 2010 Sophia Gruskin, editor of the American Journal of Public Health, and colleagues, specifically pointed to availability, accessibility, acceptability and quality as key barriers to sexual and reproductive health (Gruskin, Bogecho, & Ferguson, 2010). As evidence from the literature, this model will build on previous research to understand whether and how jurisdictional borders pose barriers to coordinated HIV prevention in each of these four dimensions, and if there are additional border-related barriers to coordinated public health that are not considered in this framework. For the purpose of this analysis, the following definitions will be used for availability, accessibility, acceptability, and accountability:

1. **Availability**: The General Comment No. 14 definition states that availability means the existence of public health and healthcare facilities in sufficient quantity; however, it specifies that "sufficient quantity" is relative to the region. The General Comment goes on to explain that services which should be in sufficient quantity to provide health to the

public includes safe drinking water, sanitation facilities, hospitals, clinics, trained medical and professional personnel receiving competitive salaries, and essential drugs (United Nations Economic and Social Council, Committee on Economic, Social, and Cultural Rights, 2000). Zuniga, et al. also describes availability of services as the existence of services, and has operationalized the definition as, "Are services available in the geographic area?" (Zuniga, et al., 2006). This operationalization of availability will be used for this study.

2. **Accessibility**: The U.N. General Comment No. 14 defines accessibility as having four overlapping dimensions: "(i) Non-discrimination: Health facilities, goods and services must be accessible to all, especially those most vulnerable; (ii) Physical accessibility: Health facilities, goods and services must be within safe physical reach to all, especially vulnerable or marginalized groups. This includes adequate access to buildings for persons with disabilities; (iii) Economic accessibility (i.e. Affordability): Health facilities, goods and services must be affordable for all, meaning that payment for services is based on the principle of equity, ensuring that poorer households are not disproportionately burdened with health expenses as compared to richer households; and (iv) Information Accessibility: Includes the right to seek, receive, and impart information and ideas concerning health issues, but does not impair the right to have personal health data treated with confidentiality." Sophia Gruskin and colleagues point out that these components require special attention to the most vulnerable and affected populations, and found this definition suitable for the field of sexual health (Gruskin, Bogecho, & Ferguson, 2010). Zuniga and colleagues defined availability simply as "service convenience or affordability," in their study of healthcare service utilization in the U.S.-

Mexico border region. In addition to the thorough definition provided by the U.N., and confirmed by the Gruskin article, the operationalization of accessibility to services as used by Zuniga and colleagues considers factors related to a border region, and therefore, will be very useful for this study. Client transportation and literacy level of materials provided by health service providers will also be considered in the definition of accessibility, as was done in the Zuniga study.

3. **Acceptability**: The U.N. General Comment No. 14 defines accessibility as, "all health facilities, goods and services must be respectful of medical ethics and culturally appropriate, as well as designed to respect confidentiality and improve the health status of those concerned." Gruskin, Bogecho, & Ferguson emphasize that health facilities, goods and services must be, "sensitive to sex and life-cycle requirements," which is also included in the UN definition. The 2006 study by Zuniga and colleagues defined acceptability as, "how congruent services are with client expectations (cultural)," and operationalized this definition as including consideration of social expectations, language needs, client comfort, as well as addressing potential stigmas.

4. **Accountability**: *Quality*, not accountability, is the fourth component of the U.N. General Comment No.14 essential elements of a rights-based approach to health. Quality is defined as, "requiring goods and services to be scientifically and medically appropriate and of good quality; specifically, skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water and adequate sanitation. While quality as described in the U.N. General Comment is important, it does not describe the mechanism for assuring quality is provided in all goods and services. For this reason, accountability seems to be a more useful component of the model. Gruskin

and colleagues defines *accountability* as "mechanisms at local, national, regional, and international levels to monitor compliance and support governments in fulfilling their human rights obligations to their populations, which impact on health and development," (Gruskin, Bogecho, & Ferguson, 2010). The Zuniga models discusses accountability as accountability of services to clients and to the community, which is a much better fit for this discussion of jurisdictional border. According to Zuniga and colleagues, accountability refers to service system responsiveness to clients and community. This does not negate, but rather builds on the previously mentioned definitions. The study by Zuniga and colleagues specifically mentions the necessity of mechanisms for consumers to participate in service decision-making or to provide feedback on services they receive.

The Matrix Method of Literature Reviews will determine whether or not the literature validates this model of public health service utilization, and whether there is evidence that public health service utilization is helped or hindered by the jurisdictional border. The goal of this study is to determine whether the literature related to organizational barriers to HIV prevention across jurisdictional borders support the Health Service Utilization Model.

2.7 Research Methodology

The methodological framework for this study is the community-based participatory research (CBPR) approach (Israel et al., 1998; Viswanathan et al., 2004). The W. K. Kellogg Foundation (2001) defines CBPR as:

> *"A collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each*

brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities."

As part of the developmental process for establishing a comprehensive Prevention Research Center, the researcher embarked on a relationship-building process between state and local health departments, community-based organizations, faith-based organizations, and community residents in 2008, which has continued to the present date. These relationships were characterized by give-and-take; at times, the researchers supported outreach and testing activities, health education or provided technical assistance services to community partners. In return, and sometimes during these service experiences, community partners helped the researcher to learn about the community and the impact of HIV on the community. In developing the research plan, recruiting participants, interpreting results, and disseminating results, community relationships have been, and continue to be a critical component of the overall research project. The goal of this dissertation is to synthesize the results of data collected through this community-based participatory research process to build on existing border theory in public health by identifying organizational barriers to HIV prevention posed by jurisdictional borders.

2.7.1 Previously collected data

In 2009, a Prevention Research Center was founded at the University of Maryland (UMD-PRC). The UMD-PRC was started to 1) scale-up community-based participatory research activity of faculty at the university, 2) expand capacity of long-standing community-university research relationships, and 3) create an infrastructure for

establishing new community partnerships that could result in mutually beneficial research projects. The UMD-PRC had a mission to reduce health disparities in a particular geographic region and while the region experiences disparities for various health outcomes, the focus for the UMD-PRC's initial research project was to reduce disparities in HIV/AIDs. The following describes the first HIV/AIDS-related data collection initiative of the center, which was guided by community advisors and the UMD-PRC administrative structure.

The University of Maryland Institutional Review Board (IRB) approved the data collection protocol and all data collection instruments. According to the approved IRB (*See Appendix A*) for this data collection process, the goal of this data collection process was to, "*… obtain information about current resources and challenges for STD/HIV prevention in Prince George's County to inform the development of an online tool for identifying STD/HIV resources, and helping STD/HIV organizations better serve community residents.*" Focus group and interview methodology was used to explore challenges to HIV prevention in a high HIV-prevalence region, and to understand stakeholder perspectives on the need for collaboration to address high HIV rates. Staff of various organizational entities who work toward HIV prevention in Prince George's County, MD, and in Washington, D.C. were invited to participate focus groups and interviews. Individual interviews were conducted with individuals in different stakeholder groups who had specialized knowledge on a topic and whose perspectives and insights were considered essential for obtaining full understanding of the STD and HIV challenges facing the region at the community organization level. The aim of this dissertation is to analyze the data to understand organizational barriers to coordinated

HIV prevention. Though these data collection activities were not conducted for the specific purpose of assessing organizational barriers to cross-jurisdictional collaboration, participants were from different jurisdictions and discussed barriers to HIV prevention, which often included discussion about the jurisdictional border.

2.7.2 Data Collection Team

The process for collecting focus group and interview data requires a team of individuals working together. I was fortunate to be working on a CDC grant at the University of Maryland Prevention Research Center, with a very talented team of individuals who supported data collection efforts. The team was led by Principal Investigator, Dr. Brad Boekeloo, and Co-Investigator, Dr. Nancy Atkinson. Community resident and retired University of Maryland faculty, Dr. Suzanne Randolph also provided technical assistance and consulting services on the project. Also, several doctoral and undergraduate students with interest and experience working with the study population assisted with data collection efforts.

Team Leaders

As Director of the UMD-Prevention Research Center, Brad Boekeloo was the PI on the project and provided mentorship and guidance, in addition to observing some of the focus groups. Dr. Boekeloo has over 25 years of research experience focused on STI/HIV prevention in adolescents and adults. He was also Director of Evaluation for several Health Resources and Service Administration (HRSA), AIDS Education and Training Centers which are multi-site HIV training programs. He was also Principal Investigator of a State funded evaluation training program for health professionals.

Nancy Atkinson, a tenure-track faculty member in the Department of Behavioral and Community Health, who had experience conducting community health research in the State of Maryland, including Prince George's County. She has served as an instructional designer, focus group coordinator and moderator, and design team member for several multi-media health education, expert system, and health communication projects. Dr. Atkinson was the PI of the Eat Smart, Be Fit, Maryland! Project, which sought to improve nutrition and physical activity behavior among low income families via an online intervention while addressing digital divide issues and won a national award for Internet Education Technology from the National Extension Association of Family and Consumer Sciences.

Community Consultant

Suzanne Randolph is a renowned expert and community leader in the study region, and has exemplary skills in group facilitation. Dr. Randolph has experience as Principal Investigator on several community-based participatory research efforts in the study region and with the study population. She served as the Community Engagement Coordinator at the Prevention Research Center, responsible for assuring cultural competency and providing CBPR training. Dr. Randolph trained doctoral students (including myself) on conducting focus groups in communities of color.

Doctoral Students

Brian Gilchrist, Chandria Jones, and Katrina Debnam had training and some experience with both quantitative and qualitative primary data collection. These students assisted the day of the focus groups as moderators, note-takers or observers. All doctoral

students had extensive experience working with African American communities, similar to the study community.

Undergraduate students

Tanisha Fuller, Felicia Tankard, and Helen had very little focus group experience, but were trained by the doctoral students, including myself, and participated as note-takers, and observers during focus groups. All undergraduate students chosen to participate in the data collection had extensive experience working with African American communities, similar to the study community.

My primarily responsibility was to ensure that the data collection occurred, planning logistics of focus groups and interviews, recruiting participants, getting data collection instruments IRB approved, and making sure we had enough staff and appropriate equipment for all activities. My experience and training with Dr. Boekeloo conducting focus groups on an NIAAA grant addressing college drinking behaviors prepared me for data collection activities for this dissertation."

Though it may be difficult for me to remain completely objective, because I am starting with some preconceived notions from interacting regularly with HIV stakeholders and community members in the study population, this community participation will likely improve the significance and usefulness of the findings. My relationship with this community and my history of working towards system-level change in this community will increase my ability to be objective in my analysis of the Health Service Utilization Model as a framework for understanding and addressing jurisdictional barriers to coordinated HIV prevention efforts. If the model is truly a good fit, then it

will benefit the community. If the model is not a good fit, this is also important to understand so as not to steer stakeholders and community members down a path that will not be fruitful.

2.7.3 Participants

Five focus groups (n= 7, 5, 9, 5, 10) and 11 individual interviews were conducted with five stakeholder groups: State health department (1 focus group, 2 interviews = 9 participants); County health department (1 focus group, 3 interviews = 8 participants); community-based organizations (CBOs) (1 focus group, 5 interviews = 14 participants); health care providers (1 focus group, 1 interview = 6 participants); and community residents (1 focus group, 10 participants). A total of 47 participants were included: 32 reported Prince George's County residence, 29 self-identified as female, and 36 self-identified as Black.

State health departments were invited to the study because representatives working at the state Department of Health and Mental Hygiene, HIV and STD Divisions have a unique perspective on how federal recommendations, federal programs, and federal dollars are distributed throughout the state to local health and social service agencies. They also have the ability to see how resources are shared across state borders, and across jurisdictional borders within the state. State health department representatives are also in position to make state policies and make decisions about how funds should be spent on HIV and STD prevention initiatives.

County health department representatives were invited to the study because they are central to many aspects of HIV prevention efforts. County health department STD and HIV surveillance and programs are often funded partially by state funds, and

therefore interact with the state health department. County health departments also employ health care providers to provide programs and direct services related to HIV prevention. Sometimes, county health departments provide funds to community-based organizations, or support community-based organizations in providing programs and services to community residents. County health departments also interact regularly with community residents through provision of programs and services. Lastly, county health departments are involved in disease surveillance, and have intimate knowledge of policy related to HIV prevention.

Community based organizations were invited to the study because these organizations work directly with community residents in need of HIV prevention services. These organizations doing much of the front-line work in HIV prevention are usually competing with each other for funds from federal, state, and county agencies. Therefore, community-based organizations would have a unique perspective on the infrastructure around HIV prevention and what may be done to improve HIV prevention for the community residents they serve.

Health care providers were invited to the study because while they are usually working inside another public health facility, these individuals provide the direct medical care to people at-risk, or infected with HIV. These individuals interact with community residents during HIV testing and treatment and have a unique perspective on availability of resources for HIV testing and treatment, and related community needs and assets.

Community residents were invited to participate in the study because it was thought that as current or potential recipients of services provided by the stakeholders

mentioned above, they may have a unique perspective on challenges and potential solutions for HIV prevention in the Washington, D.C. metropolitan region.

2.7.4 Focus Group Eligibility and Participant Recruitment

To be eligible for participation, participants had to be currently in an employed position that included HIV prevention activities, except for those in the "community resident" stakeholder group. State and county officials had to have been in the same position for the past 3 consecutive years. For CBOs, participants had to be employed at their organization for two years and have had at least 5 years of experience working with HIV. Healthcare employees had to be licensed and able to provide services. Community residents were required to be residents of the inner-beltway region of Prince George's County, because this region has high incidence of HIV, qualifying this group as part of an "at-risk" population.

Recruitment occurred through email invitation, phone calls, and word-of-mouth. For the state health department stakeholder group, members of the study's community advisory committee (CAC) who worked at the state assisted with recruitment and recommended individuals knowledgeable about HIV prevention in geographic region of interest (i.e. Prince George's County and its border with Washington, D.C.). For county health department stakeholder group, there were fewer individuals working directly with the HIV and STD clinics, so recruitment was more targeted and direct to those few individuals. For the community-based organizations, recruitment occurred once again with the assistance of members of the study's CAC. Information about the study was shared through a listserv of a regional coalition of HIV prevention organizations, and through direct recruitment where members of the research team and/or study CAC

attended meetings with community-based organizations and informed attendees about the study and the need for participants. Health care providers were recruited through emails and phone calls by the research team after a list of potential participants was generated by the CAC. While recruiting CBOs and healthcare providers for the study, they were also asked if they would be able to share information sheets about the study with representatives of the community they serve at their organization or clinic. CBOs and healthcare providers willing to help informed the researchers about how many community residents were interested and once the focus group maximum was reached, CBOs and healthcare providers were asked to stop recruiting. The site of the community focus group (i.e. a community activity center) also posted signs advertising the study.

2.7.5 Interview Participant Eligibility and Recruitment

Members of the project's Community Advisory Committee had recommended interviews with several individuals at various levels of the healthcare system. At the state health department, interviews were conducted with then-current director of HIV prevention services and then-current director of STD programs because these individuals had specialized, in-depth knowledge of HIV prevention in the state that others working at the state level did not have. Therefore, it was determined that in-depth interviews with these individuals were necessary. At the county health department level, again, the CAC recommended speaking with three individuals who had worked at the Washington, D.C. Department of Health HIV Division for an extended period of time. Due to their long histories working in the district neighboring Maryland, and the district experiencing some of the highest rates of HIV in the nation, it was determined that in-depth interviews should be conducted with these individuals, separate from the focus groups conducted

with health department officials in Maryland. For the community-based organization, there was one particular organization, which initially resided in the center of Washington, D.C., but had recently moved closer to the Maryland border. The CAC had recommended that this organization be included in the sample and that in-depth interviews be conducted to learn their perspective on HIV prevention resources and needs in the Prince George's County region bordering Washington, D.C. At the healthcare provider level, while the focus group consisted of people providing direct services to clients, the CAC recommended that an in-depth interview be conducted with an individual who was currently working in an administrative position, but who had recent previous experience as a provider in the county, and who had gained a different perspective in the new administrative role. Therefore, an independent in-depth interview was conducted with this person. Recruitment of participants for in-depth interviews occurred concurrently with focus groups and used the same recruitment protocol.

2.7.6 Procedures

Most of the data collection sessions were held in community settings that were convenient to participants, such as community centers, schools and health clinics. The state health department stakeholder focus group was held at a conference room at the state health department building. Interviews with two state employees unable to attend the focus group but interested in participating were conducted in the same building, but in the office of the individuals. The county health department stakeholder focus group was held at a local county health department and additional interviews for those unable to attend the focus group were conducted over the phone. Community-based organization stakeholder focus groups were held at a local health center and interviews were

conducted at the offices of individuals being interviewed. Health care provider focus groups were also held at the same health center as the CBO focus group. Focus groups for community residents were conducted at a community activity center. Individual interviews ranged from 30 to 60 minutes in length, and each focus group was two hours. Incentives were provided to each participant, and the focus group sessions included refreshments.

The same researchers conducted interviews and moderated focus group discussions, which also included trained student note takers. The interviewers/moderators had prior experience interviewing and moderating and were trained in probing questions and in issues related to HIV prevention in the geographic area. All focus groups and interviews were audio recorded and consent was documented from all participants, and all participants received cash incentives for participation. The entire study protocol was approved by the University of Maryland Institutional Review Board prior to the study, and the protocol remains open for continued data analysis.

A semi-structured guide of open-ended questions facilitated conversations with participants and focused on HIV prevention in their communities and the challenges and strengths of doing HIV prevention work with others in the geographic vicinity (*See Appendix B for IRB Approved Moderator Guide*). The same questions were used in both the interviews and the focus groups. The guide asked participants to discuss perceptions of and experiences with STD/HIV prevention in the Washington, D.C. metropolitan area – specifically Prince George's County, as well as perceived benefits to and challenges with collaboration for STD/HIV Prevention in the region, and their opinion about the concept of an online system to facilitate better collaboration in the region.

2.7.7 **Mixed Methods**

Both focus group and in-depth interview data will be analyzed and triangulated to explore organizational barriers to coordinated HIV prevention across jurisdictional borders. Focus groups are defined as, "*a carefully planned series of discussions designed to obtain perceptions on a defined are of interest in a permissive, nonthreatening environment*" (Krueger & Casey 3rd ed. Pg. 5). Focus groups differ from individual interviews, in that focus groups depend on the exchange of ideas among participants as much as they also rely on answers to the moderator's questions (Ulin, Robinson, & Tolley, 2005, p. 89). Analysis of focus group data will allow for exploration of how HIV prevention stakeholders discuss organizational barriers to coordinated HIV prevention with each other in a group setting, the extent to which they speak openly about this topic, and whether or not there is agreement on different aspects or themes related to cross-jurisdictional collaboration.

In-depth interviews are usually an exchange of between interviewer and respondent (Uler, Robinson & Tolley, 2005, p. 81), where both the interviewer and respondent, "*work together to achieve a shared goal of understanding*" (Rubin & Rubin 1995, p. 5, in Uler, Robinson & Tolley, 2005, p. 82). In-depth interviews add to this study because they allow stakeholders with a special position, perspective, or knowledge-base to share information on what could be considered a sensitive topic, in an environment that is "comfortable, relaxed, and non-threatening," and without the presence of others who may be competitors, or may be judgmental of comments or opinions.

Use of both focus groups and in-depth interviews contributes triangulation of data. Triangulation of data is a method proven to establish the validity of qualitative studies, wherein results are considered more likely to be valid when different methods of data collection lead to the same result (Leech & Onwuegbuzie, 2007). If both focus group and in-depth interview data support the same themes after analysis, the researcher can be more confident that the results are valid since two different methods of data collection provide the same result. If different themes emerge in focus group versus interview data, it would be important to explore why there might be differences and what meaning can be derived from themes discussed in a group setting, but not in a smaller discussion, and vice versa.

To determine whether there is data to support an existing model of health service utilization as a framework for understanding organizational barriers to coordinated HIV prevention across jurisdictional borders, a thematic analysis approach will be utilized on previously collected focus group and interview data. The proposed research plan is to analyze this data to determine support for the health service utilization model as a framework for in-depth understanding of barriers to coordinated HIV prevention across jurisdictional borders.

2.7.8 Detailed Description of the Survey of HIV Prevention Organizations

When the qualitative data previously collected, an exploratory, grounded theory analysis was conducted to discover emergent themes that were important to stakeholders, which could be explored further quantitatively. Therefore, data from stakeholder focus groups along with extant literature on measures of collaboration, and constructs from the Health Belief Model were used to inform the development of a survey that would assess

HIV Prevention Organizations' (HPOs') perceptions of cross- jurisdictional collaboration. The "barriers" construct of the Health Belief Model was part of the development of the data collection guides. The focus group moderator's guide and the survey both asked participants to discuss any perceived barriers or challenges to HIV prevention in the study region. This affects what data was collected, and thus will influence the development of the theory that emerges from the data. The survey was developed to assess collaboration between organizations on both sides of the jurisdictional border that provide services to populations in both the suburb and the urban jurisdiction. Sections 3.3.2 and 3.3.3 describe how this data was collected and Section 2.7.9 describes the planned analysis that will respond to research question, "*What are the organizational barriers to cross-jurisdictional collaboration*?"

Sample. HIV Prevention Organizations were defined as organizations that have the capacity to provide HIV prevention services (i.e. condom distribution, education, and testing) to residents living in the high-morbidity, urban and suburban border region. In developing a sample for the study, it was determined that there was no single list including HIV Prevention Organizations (HPOs) located in the entire affected region (i.e. both Washington, D.C., and border suburb, Prince George's County). Therefore, the first challenge in the study was to define the study sample. To resolve this challenge, the research team developed a 4-step strategy to identify HPOs for the sample. First, existing lists of HIV Prevention Organizations (HPOs) in the region were identified and added to the sampling frame. Next, online searchers were conducted using key terms, such as "HIV prevention AND [county or city name]" or "condom distribution AND [county or city name]." Any additional organizations found through this online search were added

to the sampling frame. Then, as part of a series of focus groups and interviews, stakeholders were asked to identify HIV prevention providers in the region. The last part of the strategy was community event attendance. Over one-year period, 15 HIV prevention events in the region, focused at least in part on the suburb, were attended. Attendance at these events also served to develop community relationships, which were critical to the community-based participatory research approach. Attendance lists and discussions at events were used to identify HPOs serving the suburb. Community event attendance was a critical step in developing the sampling frame for the study because: (1) some HPOs lacked a functioning, informative website, (2) some existing organizations had only recently added HIV prevention services, or (3) the HPO was so recently funded to provide HIV prevention services to the study community, the HPO had yet to implement services. After one year of the processes described above, the final sampling frame contained 55 organizations that provided HIV prevention services in the border region. Criteria were developed to include only HPOs who had a visible community presence, exemplified either through multiple community events attendance or by being known to stakeholders in addition to having a strong online presence, making them easily identified as HPOs. Organizations were included in the sample if they 1) were mentioned by in stakeholder interviews or focus groups and one event or 2) appeared at two or more events. Based on these criteria, the final sample included 30 HPOs; 15 urban and 15 suburban.

The 30 HPOs included in the sample were contacted via email and phone and invited to participate in a one-hour, close-ended face-to-face survey about cross-jurisdictional collaboration. Initial attempts were made to contact heads of organizations;

however, in 13 cases, executives asked Program Directors or knowledgeable others to represent them in the interview. Participants were invited to complete the survey over lunch or dinner, and were provided with a token of appreciation worth $20. Three participants requested administration of the interview over the phone or via email. Ultimately, 26 interviews were conducted: 23 interviews were face-to-face and 3 surveys were completed with a combination of phone and emailed responses. In many cases, multiple individuals were needed to answer all the survey questions (n=16); other times, only one individual was able to answer all of the questions about the organization (n=10). Non-participation occurred for various reasons: Two organizations claimed they were ineligible because they were not direct service providers. One organization claimed they needed approval from a collaborator and after several emails, phone calls, and in-person meetings permission was unobtainable. At one organization, the researcher was referred to an individual who went on maternity leave and did not have enough time for an interview upon return.

Data Collection. After a thorough review of the literature, survey items were created by the researchers and presented to a community advisory committee (CAC) for feedback and revision. The committee's final draft was then pre-tested with leaders at two HIV prevention organizations located slightly outside of the sample region. Pre-test results were applied and the final survey was presented to the community advisory committee one last time before sending the survey for institutional review. The Institutional Review Board at the University of Maryland approved the survey and the data collection protocol (*See Appendix A*). All interviews were conducted by one researcher who had some familiarity with HIV prevention organizations. Interview

responses were recorded and verified by the respondent before the interview concluded. De-identified data were entered into a database in SPSS version 19 for analysis.

2.7.9 Planned Analysis of Survey Data

HIV Prevention Organizations (HPOs) are the unit of analysis for this study. As stated in section 1.3 of this proposal, *HIV Prevention Organization* is defined as an organization that provides HIV prevention services (i.e. condom distribution, education, counseling, testing, and referral) to residents living in the high-morbidity, urban-suburban border region. More information about how HPO was defined for this study can be obtained from the description of the study sample, in 2.7.8 section above. The population of HIV Prevention Organizations meeting the study eligibility criteria was 30, and 26 of those HPOs participated in the study. This small sample size would likely lead to violation of assumptions for most parametric statistical analyses. Therefore, nonparametric statistics were used to analyze these data. Nonparametric statistics can offer robust analysis of categorical or ordinal data, and typically uses rank order, median or frequencies when comparing samples or determining significance (Pett, 1997, p. 17). According to Marjorie A Pett, in her book, "Nonparametric Statistics for Health Care Research," nonparametric statistics are underused in research (p.18). Several possible reasons for this have been hypothesized, but not tested. Unfortunately, researchers often conduct parametric statistical analyses, even though their data may be violating some assumptions or the parameters on which parametric statistical tests rely. For this reason, it is argued that nonparametric statistics, which do not rely on such parameters, can be more robust than parametric statistics (p. 17).

The analyses for this study will occur in three phases. First, the sample of organizations will be described by several key variables related to capacity, collaboration, and service provided. Next, barriers to coordinated HIV prevention across the jurisdictional border will be examined for whether the data show evidence that barriers exist, and what barriers are identified most often. Finally, significant correlations between measures of barriers and measures of sample characteristics of HIV prevention organizations will be explored through nonparametric tests of associations between variables.

Part 1: Sample Description Data Analysis

The HPOs participating in the sample will be described in terms of their capacity to provide services, the services they provide, and their reported collaborative activity with HPOs on the other side of the jurisdictional border.

Capacity to provide services in the jurisdictional border region

Several questions were asked to measure capacity of each HPO in the study. An organization's capacity has been defined in the literature in various ways depending on the context. Fredericksen and London have identified and defined four main components of organization capacity through their work with Community-Based Development Organizations (CBDOs) in the U.S.-Mexico Border region (Fredericksen & London, 2000). In exploring whether CBDOs had the capacity to partner with the state government agencies to deliver services and effectively administer projects, they defined capacity as evidence of 1) leadership and vision (e.g. is there a directing board, mission, vision, etc.), 2) management and planning (e.g. are there policies and procedures, a

strategic plan, a budget, etc.), 3) fiscal planning and practice (e.g. how are primary sources of funds generated and are these funds predictable, etc.), and 4) operational support (e.g. are staff skilled, what is the staff to volunteer ratio, is there predictability in the quality of staff, etc.). In recognition of the need to build organizational capacity for more effective HIV prevention, Jeanette Nu'Man, and colleagues at Macro International, Inc. collaborated with CDC to test an integrated capacity building framework, which emphasized the following major components of organizational capacity, specifically related to HIV prevention: 1) evidence of program implementation, 2) evaluation activities, 3) dissemination of findings, 4) report and grant-writing to obtain additional funding, 5) internal assessments of resource allocation and program improvement (Nu'Man J, King W, Bhalakia A, & Criss S, 2007). Building on what is known about measuring organization capacity; the following variables will be examined to understand capacity of HPOs in the sample: total annual income, source of funds, and number of full-time, part-time, and volunteer staff.

Total annual income: Survey question 8.3 (*See Appendix C)*, asked participants to choose one of eight response options that best categorized their organization's annual operating budget. The response options are: 0 - $49,000, $50,000 - $99,999, $100,000 - $249,999, $250,000 - $499,999, $500,000 – 1 million dollars, 1 million – 5 million, 5 million – 10 million dollars, 10 million – 15 million dollars, and Over 15 million dollars. These categories are mutually exclusive and ordinal. Participants were asked to only choose one option, which best described their organization. Frequency analysis will describe the annual income of HPOs in the sample.

Sources of funding: Survey questions 8.8 and 8.9 (*See Appendix C*), asked HPOs to estimate the percent of their current HIV prevention budget which came from public, private, federal, state, county, and local sources. These were open-ended questions, where participants were simply asked to report a percentage. Frequency analysis will describe the percent of funds obtained from each source for the sample.

HPO Staff: Questions regarding HPOs total number of staff and type of staff were asked as indicators of operational capacity. Survey questions 8.1.1-8.1.15 (*See Appendix C*) ask HPOs about the number of staff who work in different roles at the HPO. Survey question 8.1.16 asked HPOs the total number of staff at the organization, and the sum of questions 8.1.1-8.1.15 was compared with this total during the interview to verify that the information was reported accurately. Frequency analysis will describe the percent of HPOs with a total number of staff in each category. A median split will be used to describe HPOs who have staff above and below the median for each category, and for the total number of staff reported.

Services provided by the HPO

Consistent with Jeanette Nu'Man and colleagues' description of HIV prevention organization's capacity, programs and activities will be considered in our description of the capacity of HPOs in the sample. Survey questions 2.3.1 – 2.3.18 ask HPOs whether they serve various populations (*See Appendix C*) considered HIV-vulnerable. Participants could respond either, "Yes," they serve the population; "No," they do not serve the population; or "Don't know," indicating they are unsure whether the specific population has received services from the HPO in the past year. This is a dichotomous, categorical variable. Frequency analysis of the "Yes" responses will describe which

HIV-vulnerable populations are served by the sample. HPOs were also asked about their expertise with each of these populations in questions 4.2.1 – 4.2.18, and could respond that expertise was either, "Low," "Moderate," "High," or that they "Don't know." This ordinal variable will be assessed using frequency analysis to describe where HPOs in the sample have the greatest expertise with HIV-vulnerable populations.

To describe the types of services provided by HPOs in the sample, participants were asked to rate their expertise in four service areas using the same ordinal response options as in questions 4.2.1 – 4.2.18. The four service areas are 1) Education/Training/Counseling, 2) Health and medical services, 3) Basic Social Services, and 4) Financial Support Services. Education/Training/Counseling was defined as, "*Group or individual counseling and/or education, outreach education, spiritual guidance, peer training, educational programs, etc*." Health and medical services were defined as, "*Screening, preventive treatment, condom and/or contraception distribution, health system navigation, referrals, therapies, rehabilitation and other clinical services, etc.*" Basic Social Services were defined as, "*Housing, legal services, employment, food, clothing, transportation, etc*." Financial Support Services were defined as, "Grants, contracts, loans, etc." Frequencies will be used to describe the service expertise of HPOs in the sample.

Reported Collaboration across Jurisdictional Borders

To understand whether collaboration across the jurisdictional border was currently occurring, HPOs were asked to respond "Yes," or "No" about whether they currently collaborate with organizations on the other side of the jurisdictional border in question 5.3. For this question, collaboration was defined as, "by providing services to

residents or partnering on events and/or programs." HPOs were shown a map (*See Appendix C*) of the Washington, D.C. metropolitan area, which included all areas surrounding the National Capital Beltway and shaded the Prince George's County region inside the beltway, known as the "inner Beltway." Organizations were then asked to list each organization they currently partner with across the jurisdictional border. Frequencies will be conducted to determine the percent of organizations in the sample who reported cross- jurisdictional collaboration in the past year. The number of organizations listed in text will be tallied and this sum will be used to describe the extent that HPOs have collaborated across the jurisdictional border in the past year. Questions 5.5.1 and 5.5.2 ask HPOs to estimate the percent of the organization's overall effort (in percent of staff time) that is spent in Prince George's County and in Washington, D.C. This may be an indicator of current HPO activity across the jurisdictional border. Participants responded by estimating a percentage. Frequency analysis will describe the number and percent of organizations that spend effort across a jurisdictional border. Depending on the distribution of the responses, responses may be combined into categories, for example, to describe HPOs who spend less than 10% effort in another jurisdiction, between 10-25%, and so on. These categories will be created based on the range of percentages reported by the sample.

Finally, in Section 3, the number of Prince George's County residents served per year by Washington, D.C. vs. Prince George's County (PGC) HPOs will be derived after multiplying the total number served in an average year by the percent who are PGC residents. This number will be calculated for each service area (i.e. Education/Training/Counseling, Health and Medical Services, Basic Social Services, and

Financial Support Services). The resulting product from multiplying these variables will inform us about the volume of patients from PGC who are seeking services across the border in Washington, D.C.

Part 2: Barriers to coordinated HIV prevention across the jurisdictional border

Whether or not an organization has declared that working across the jurisdictional border may indicate a barrier or lack of a barrier to coordination of HIV prevention across the jurisdictional border. Survey item 2.2 describes whether each organization has a cross- jurisdictional mission. Participants were asked, "*Does this location describe the population corresponding to your organizations mission: Prince George's County; Washington, D.C.*" Response options were dichotomous: "Yes," or "No." If a Washington, D.C. HPO responds 'yes' to Washington, D.C. and 'no' to Prince George's County, Maryland, this would indicate no cross- jurisdictional mission. If a Washington, D.C. HPO responds 'yes' to Washington, D.C. and 'yes' to Prince George's County, Maryland, this indicates a cross- jurisdictional mission. If Washington, D.C. HPO responds 'no' to Washington, D.C. and 'yes' to Prince George's County, Maryland, this could indicate that the question was not answered accurately.

Similar to the question regarding cross- jurisdictional mission, in Section 5, participants were asked about cross- jurisdictional goals. This is a measure of interest in collaborating across the jurisdictional border. In question 5.1, HPOs were asked "over the last 12 months, to what level did your organization achieve its HIV prevention goals in Washington, D.C. and Prince George's County. The ordinal response options provide were, "we have no goals in this area," "no goals met," "goals partially met," and "goals exceeded." Frequency analysis will describe whether organizations perceive that they

have been successful in their work across the jurisdictional border. Previous collaborative experiences can predict future collaboration, and can therefore be indicators of barriers or facilitators to future collaboration (Powell, Koput, & Smith-Doerr, 1996). Also, if a high frequency of HPOs report no goals in the bordering jurisdiction, this lack of goals would be a barrier to coordinated HIV prevention across a jurisdictional border.

In addition to asking whether an HPO had current goals across the jurisdictional border, survey question 5.2 asked HPOs if they had any plans to expand their HIV prevention goals in these geographic regions in the next 12 months. Response options were "no expansion," "minor expansion," and "major expansion." These response options will be coded as 0 for no expansion, 1 for minor expansion and 2 for major expansion. Frequency analysis will be conducted to determine what percent of organizations plan to expand across the jurisdictional border in the future, and how many would describe that expansion as "minor" versus "major" expansion. Organizations that do not plan to expand services and activities across the jurisdictional border are not likely to do so, and therefore, this would be a barrier to future coordinated HIV prevention across a jurisdictional border.

Section 6 of the survey asks questions about factors influencing cross-jurisdictional collaboration. HPOs were asked to, "describe the extent to which each [factor] is a barrier for your organization to work across the Washington, D.C. / Prince George's County border, by responding, not at all, very little, somewhat, or a lot." HPOs were asked whether the following factors were barriers: competition for funding, lack of time and energy, similarity in mission and services, fear of loss of client trust, negative prior experiences, lack of follow-up, negotiation of leadership, lack of incentives for

collaboration, and discomfort discussing sensitive topics related to STD and HIV prevention. Frequency analysis will be conducted to determine the most important barriers influencing cross-jurisdictional collaboration by HPOs in the sample.

Part 3: Exploratory correlation analysis of barriers to collaboration and characteristics of HPOs

Exploratory correlation analysis was conducted to determine whether there are associations between barriers to coordinated HIV prevention (as they have been described in Part 2) and sample characteristics described in Part 1, specifically, capacity and reported cross-jurisdictional collaborative activity. Nonparametric tests of association were used to conduct this exploratory analysis. Since all of the variables discussed above are at least at the ordinal level of measurement, Spearman's rho will be used to conduct the nonparametric test of association. Spearman's rho is more commonly used in health research, and more closely resembles the parametric equivalent, Pearson's product-moment correlation coefficient (r) (Pett, 1997, p. 275). Spearman's rho statistic can be calculated in SPSS with the data obtained from this sample of HPOs. Strength of each correlation, as well as whether or not each correlation is statistically significant will be reported in the results. Correlations between two variables will demonstrate relationships between characteristics of HPOs and barriers to collaboration; however, this exploratory analysis will not provide causal conclusions about the relationship between organizational barriers to coordinated HIV prevention across jurisdictional borders.

2.8 Matrix Method of Literature Reviews

To identify previous research examining *organizational barriers to coordinated HIV prevention across jurisdictional borders* and to inform the qualitative focus group analysis, the Matrix Method of Literature Reviews will be utilized (Gerrard, 2011; Goldman & Schmalz, 2004). The Matrix Method of Literature Review (MMLR) provides a precise, systematic strategy for reading, analyzing and summarizing scholarly material on a specific topic. MMLR was specifically designed for reviews of the health sciences literature (Gerrard, 2011). The MMLR is defined as, "*a structure and process for systematically reviewing the literature and a system for bringing order out of the chaos of too much information spread across too many places*," (Goldman & Schmalz, 2004). The MMLR is being used as methodology for this study of *organizational barriers to coordinated HIV prevention across a jurisdictional border*, because of several benefits of using the MMLR over other methods of literature review. First, the MMLR makes identifying gaps in the literature and also predominant themes in the literature easy to see in a visual format. Second, MMLRs clear format for tracking search results allows for method replication. Lastly, the organization of literature in MMLR shows where authors or groups of authors agree, disagree, and build on each other's work.

There are four main components of the MMLR: 1) Paper trail, 2) Document File, 3) Review Matrix, and 4) Synthesis. The paper trail is a record of the search process used to identify relevant materials. This is where the researcher will blog, journal, or maintain memos of the entire search process. Relevant materials described in the paper trail may include lists of keywords, key sources, electronic bibliographic databases and related searches, internet searches, and other notes. The document file is simply a folder where

each of the downloaded files, PDF's or links to documents are kept and organized. The most unique component of MMLR is the Review Matrix, giving MMLR its name. The Review Matrix consists of rows, columns and cells, as in a basic Microsoft Excel spreadsheet. This spreadsheet is used to abstract information from each piece of literature identified in the MMLR process. The columns of the matrix can be very general or very specific, and are used to categorize the article in some meaningful way. Columns may also be used for logistical information like how to locate an article or file. Each row of the matrix represents a specific piece of literature (e.g. journal article, study, book, government report, dissertation, periodical, etc.). Each cell in the matrix includes column-related notes about the piece of literature in the cell's row. Finally, the synthesis is the part of the MMLR where the review of the literature is written based on the abstraction of articles in the matrix. These four components are built throughout the MMLR process. The four step process of conducting the MMLR includes: (1) Identify search terms and search methods, (2) Select and organize documents for review, (3) Abstract the research literature, and (4) Synthesis of the literature from the matrix.

2.8.1 Identifying search terms and search methods.

An initial list of key terms will be identified during a review of major references related to HIV prevention, coordination of HIV prevention, and organizational barriers to healthcare across jurisdictional borders. Once an initial list of keywords is created, controlled vocabulary words will be identified from the PubMed MeSH database. This list of keywords will be used for searches of various sources of data for MMLR.

Sources of Data for MMLR. The research question relates to the social and political climate, which changes with time – even though the theory-related to the

question is timeless. In order of timeliness of the science, the most recent, cutting edge, peer-reviewed research on a topic can be found through abstracts presented at scientific meetings, then online journals, then annual reviews, and lastly books in print. For this research project, primary sources of data will be sought first, as will sources from online journals. Grey literature, defined as "publications such as papers presented at meetings, technical reports, or government reports not produced by commercial publishers," (Gerrard, 2011) will also be sought as part of the review of the literature on *organizational barriers to coordinated HIV prevention across jurisdictional borders*. For all of the sources mentioned above, keywords and controlled vocabulary words will be used, starting with broad terms and ending with more specific terms. Key terms from the research question and the Health Service Utilization Model will be entered into the National Library of Medicine's PubMed MeSH terms database.[1] The results of the search for MeSH terms will be compiled into a key terms document. The key terms document will serve as the basis for the PubMed search for articles related to the research question and the components of the HSUM. Each search will be logged in an *electronic bibliographic database document* to track how each piece of literature was found and reduce the risk of repeated or redundant searches. When searches of the key terms and combinations of key terms and MeSH terms begin to bring up duplicate articles, the searching will be completed and all search results will be entered into the MS Excel Literature Matrix for further review.

[1] PubMed MeSH Terms database: http://www.ncbi.nlm.nih.gov/mesh/

2.8.2 Select and organize documents for review.

Titles resulting from each keyword search query will be skimmed to determine whether or not they should be included in the literature review. Titles that address the research question, "*what are organizational barriers to coordinated HIV prevention across jurisdictional borders?*" will be added to the Literature Matrix and electronic copies of the source will be obtained and stored in the "Document Folder." Each article will have its own line in the literature database, and the columns in the database will indicate a reference number for the article and the search which produced the article. Each row will also contain the category of the search, the specific search terms and search syntax used to produce the article, and then the article reference information (i.e., author(s), title, journal, and year). The literature matrix will also have columns for abstracting article purpose, methods and key findings, which will help in ranking the articles. Column headers related to the research questions will also be used to rank the articles. Articles which relate to the following pre-determined categories will be ranked as follows:

A = Articles which include discussion of borders, HIV, and health services

B = Articles which include discussion of borders and health services

C = Articles which include discussion of HIV and health services.

D = Articles which include discussion of HIV and borders

Higher ranked articles will be reviewed first, and will be considered more important in defining terms in the code dictionary. A-ranked articles will be reviewed first for barriers to coordinated HIV prevention across state jurisdictional borders. Where there is ambiguity or confusion about ranking an article, the article will be reviewed for

whether it relates to any of the following categories: *organizational barrier, border-related barrier, coordinated HIV prevention, need to address jurisdictional border, borders as a barrier to health, borders as a barrier to HIV prevention, trust, border-based discrimination and disparity, cultural differences, economic differences, agency/organization, HIV/AIDS prevention, state/jurisdictional border, coordination/cooperation, collaboration on specific issues, barriers/challenges, and metropolitan area/urban area..*

2.8.3 Abstract the research literature

For each title added to the Literature Matrix, information from the abstract, and later the entire article, will be sorted into columns of the matrix. Each article will be one row in the matrix, and each row will have corresponding columns. The first few columns will be used for reference and organizational purposes; for example, title, author, journal, year, search term used to identify article, etc. Articles will be reviewed according to HSUM category. For example, first, all articles related to Accountability (i.e. articles resulting from keyword searches related to Accountability) will be reviewed and ranked before moving on to articles in a different category. Next, using the title of the article and citation information, a first attempt will be made to rank the articles from A-D. Articles which do not relate to borders, HIV, or health services will not be ranked. After this first attempt at ranking articles based on title and citation information, the abstracts of each article will be reviewed to determine appropriate ranking. In situations where abstracts are unavailable, full-text articles will be sought to continue ranking. All A-ranked articles will be downloaded for further review, and information from the articles will be entered into the literature matrix. Information related to the research question,

"*what are the organizational barriers to coordinated HIV prevention across jurisdictional borders*?" and information which helps to define borders and HSUM constructs will be abstracted from the articles and entered into the literature matrix.

2.8.4 Synthesis of the literature from the matrix

The completed literature matrix will be reviewed to identify commonalities across articles with regard to the research question. For example, articles mentioning specific organizational barriers will be grouped together. Frequently occurring themes related to the constructs of the Health Service Utilization Model will be used to define terms in the codebook for analysis of qualitative data. Common organizational barriers to coordinated HIV prevention across jurisdictional borders identified through the literature review will be used to inform the codebook for the qualitative analysis described in section 3.2, below.

Chapter 3 Manuscript 1: HIV Prevention Organizations' expertise in serving HIV-vulnerable populations: Investigating community concerns

This manuscript achieves aim 1 of this dissertation: To examine stakeholder perceptions of HIV prevention challenges, and the extent to which there are disconnects between the services available to vulnerable populations.

3.1 Abstract

BACKGROUND: People Living with HIV/AIDS (PLWH/A) and others affected have expressed that cultural differences between patients and providers can create barriers to care and prevention. These barriers are exacerbated in the case of vulnerable populations who are often marginalized by society. During the formative phase of a community-based participatory research process, the researchers' Community Advisory Committee (CAC) and HIV stakeholders shared anecdotes of incongruencies between needs of HIV-vulnerable populations and expertise of local providers. In response, researchers worked with the CAC to develop survey questions intended for providers of HIV prevention services in a region afflicted with some of the highest HIV prevalence rates in the country.

OBJECTIVE: The objective of this study was to identify and validate HIV stakeholders' perceptions about challenges to provision of HIV services through a sequential mixed methods study design.

METHODS: Thirty HPOs were identified as local leaders in HIV prevention by community stakeholders and through community event attendance. Each HPO was invited to participate in an interview-administered survey examining population-specific expertise and service for 15 HIV-vulnerable populations. Frequency analysis was used to compare HPOs' expertise relative to who they serve (n=26).

RESULTS: While 13 of the HIV-vulnerable populations were served by over 50% of the HPOs, only 2 of these 13 populations were served with high expertise by more than half of the HPOs in the sample.

CONCLUSION: These data give credence to the CAC's concern regarding misalliance between whom HPOs serve and with whom they have high expertise, a factor potentially influencing HIV outcomes among HIV-vulnerable populations.

Keywords: HIV; AIDS; medical home; patient-centered care; vulnerable populations; health status disparities

3.2 Introduction

A recent study modeling the future of the HIV epidemic in the United States projected that without rapid scale-up of HIV prevention services, the HIV epidemic will greatly worsen; the status quo will lead to a 29% increase in HIV prevalence over the next ten years.(1) There is an urgent need to examine current HIV service delivery, and to identify gaps as well as areas for improvement. Several studies explore collaboration (2-4) and development of organization capacity (5) to improve delivery of medical and social services. (6-8) Stakeholders in HIV prevention expressed interest in applying

similar strategies to improve the system of HIV prevention and care services in the region. This study describes initial findings from a community-based participatory research (CBPR) effort to examine disparate rates of HIV in high- and low-resource communities. The research team partnered with a Community Advisory Committee (CAC) to explore HIV stakeholders' perceptions about challenges to provision of HIV services. The CBPR process guided the implementation of a qualitative study, involving stakeholder focus groups and interviews, which were followed by a survey of HIV Prevention Organizations (HPOs).

HIV infects the most vulnerable populations. While the risk of contracting HIV is widespread, federal, state, and local HIV surveillance data identify several populations disproportionately burdened with HIV, particularly: gay/bisexual, African American, Latino, Intravenous Drug Users, and Transgender populations.(9,10) For example, Men who have Sex with Men (MSM) represented about four percent of the U.S. population in 2010, (11) and 78% of new HIV infections.(12,13) A recent meta-analysis of 145 MSM studies from 1981-2011 found that compared with nonblack MSM, Black MSM have less access to care and HIV treatment.(14) Vulnerable populations may have limited access to facilitators of HIV prevention, such as economic resources, supportive societal attitudes, and inclusive organizational structures. (15, 16)

Public health service delivery to vulnerable populations. Vulnerable populations are defined as populations at-risk for poor physical, psychological, or social health.(17) People Living with HIV/AIDS (PLWH/A) and those most-at-risk of infection often belong to groups with particular characteristics (e.g., sex workers, injecting drug (ID)

users, prisoners, youth, MSM, etc.) and social and institutional norms delimiting their social acceptance leads to social marginalization.(18) Such marginalized groups may have difficulty accessing the healthcare system based on fear of deportation, imprisonment, further stigmatization or additional financial burden.(17,19) Vulnerable populations' interactions with health systems warrant further study because these populations' health needs are frequently not addressed.(17,19,20) The healthcare system's inability to reach vulnerable populations prior to HIV disease progression places high demands on often limited social and medical service resources.(20, 21)

HIV Prevention Organizations need expertise with vulnerable populations. Those most vulnerable to HIV face special challenges in obtaining health services and development of service delivery models for those most-at-risk for HIV has proven to be complex. While HPOs are challenged by having to constantly respond to new HIV practice guidelines and changes in health care systems and policies (22), ensuring culturally competent service to vulnerable populations adds another level of difficulty. Having expertise in service delivery for prevention and treatment of HIV could be defined as providing services that are culturally appropriate for the population, including effectively using the language of the population, acknowledging access barriers, and recognizing the vulnerabilities due to marginalization in the broader community. (18)

Present Study. The objective of this study was to identify HIV stakeholders' perceptions about challenges to provision of HIV services through systematic sequential examination of stakeholder focus groups and interviews, followed by a survey of HIV prevention organizations.

3.3 Methods

Mixed Methods, Community-Based Approach.

An exploratory, sequential, mixed methods research design using a community-based participatory approach was implemented to study challenges and opportunities for HIV prevention in a high prevalence metropolitan area. The sequence included: 1) formation of a Community Advisory Committee, 2) implementation of a focus group and interview study, and 3) implementation of a survey study. All study instruments and recruitment procedures were vetted with the CAC prior to receiving approval from the Institutional Review Board of the researchers' academic institution.

Community Advisory Committee Formation. First, a Community Advisory Committee (CAC) was convened to identify research priorities and provide feedback on all activities. A semi-structured, snowball recruitment process was initiated to obtain membership in the CAC. After consulting with an existing community-university partnership for guidance, meetings were set up with state and local health department employees who then referred the researchers to others with topical and local expertise. The stakeholder groups formally participating on the CAC included: representatives from state and local health department STD and HIV programs, local community-based organizations providing HIV prevention services, city government and community leaders, and community residents residing within zip codes experiencing the highest rates of HIV in the region. Public health official representation from the neighboring city was recommended by CAC members because there is high geographic mobility of vulnerable populations across area borders and joint resource priorities.

3.3.1 Qualitative Study

The established CAC recommended a qualitative, exploratory study with seven stakeholder groups. The groups identified as stakeholders were thought to have the ability to impact those living with or at risk for HIV. The listing of these stakeholder groups, along with the type of qualitative data collection and number of participants, is as follows: 1) State Health Department representatives (1 focus group, 2 interviews = 9 participants), 2) County Health Department representatives (1 focus group, 3 interviews = 8 participants), 3) Community-Based Organizations (1 focus group, 5 interviews = 14 participants), 4) Medical Personnel (1 focus group, 1 interview = 6 participants), 5) Funding agencies (4 interviews), 6) University students (1 focus group = 7 participants), and 7) Community residents (1 focus group, 10 participants). There were 59 total participants in the study. Participants were predominantly African American (66%) and female (63%).

Study recruitment. The CAC brainstormed a list of potential participants for each stakeholder group, and established the eligibility criteria. The goal was to recruit participants who had intimate knowledge of different aspects of local HIV prevention policy, services and population outcomes. The research team then contacted these individuals and a snowball sampling approach ensued, where contacted individuals invited other stakeholders to participate in the study. A listserv of a regional STD coalition was also used to promote the study to potential participants. Though stakeholders were recruited to participate in focus groups, interviews were conducted with interested stakeholders who met study criteria, but were unable to attend the focus group session. To get a large variety of perspectives from each group and attempt to

reduce the potential for bias (e.g., from a group who all know each other or all work together), the goal was to obtain at least 10 participants per stakeholder group. Table 1 explains eligibility criteria and response rate for each stakeholder group.

Table 1: Eligibility criteria and response rate for qualitative study

Eligibility criteria	Number recruited	Number participating	Response Rate
State government stakeholders			
• Participant(s) must be a current employee at a government agency • The government agency must have the ability to directly or indirectly provide services to residents of Prince George's County, Maryland. • Participant(s) must have been employed at current agency for at least 3 years • Participant(s) should be potentially involved in STD/HIV prevention. • Previous participation in a focus group or interview would make one ineligible for the study.	10	9	90%
County government stakeholders			
• Participant(s) must be a current employee at a government agency • The government agency must have the ability to directly or indirectly provide services to residents of Prince George's County, Maryland. • Participant(s) must have been employed at current agency for at least 3 years • Participant(s) should be potentially involved in STD/HIV prevention. • Previous participation in a focus group or interview would make one ineligible for the study.	10	9	90%
Community-based organization stakeholders			
• Participant(s) must be a current employee at a Community-Based Organization (CBO) or Non-Profit agency that has STD/HIV prevention as its primary function. • The CBO or Non-profit must directly or indirectly provide services to residents of Prince George's County, Maryland. • Participant(s) must have been employed at current organization for at least two years, and have at least 5 years of experience working in the Washington, DC metropolitan	10	14	140%[a]

Eligibility criteria	Number recruited	Number participating	Response Rate
area. • Participant(s) should be potentially involved in STD/HIV prevention. • Previous participation in a focus group or interview would make one ineligible for the study.			
Medical personnel			
• Participant(s) must be currently licensed to work with patients • Participant(s) must be currently employed in a position to provide STD/HIV prevention services to the general public, including but not limited to residents of Prince George's County, Maryland. • Participant(s) should be potentially involved in STD/HIV prevention. • Previous participation in a focus group or interview would make one ineligible for the study.	10	6	60%
Community Residents			
• Participants must be male or female, depending on focus group • Participants must be residents of Prince George's County, for at least 3 years • Participants cannot be students at the University of Maryland, • Participants must be infected, at-risk, or otherwise impacted by STD/HIV • Participants must be potential user of STD/HIV prevention information or resources • Previous participation in a focus group or interview would make one ineligible for the study.	10	10	100%
University Students			
• Participants must be students at the University of Maryland • Participants must have evidence of interest and/or experience in STD/HIV prevention • Previous participation in a focus group or interview would make one ineligible for the study.	10	7	70%

[a]Additional participants showed up during the individual interviews, so we ended up with more than 10 individuals participating, even though only 10 were confirmed to be participants.

Study implementation. Focus groups and interviews were held at locations convenient to participants in community centers and county health facilities. The individual interviews ranged from 30 to 60 minutes, and each focus group lasted two hours. Incentives were offered to each participant in appreciation of their time, and refreshments were served during focus groups. Participants were asked to discuss challenges and opportunities for HIV prevention and perceptions related to inter-organizational collaboration. All focus groups and interviews were digitally recorded and had two note takers, one observer, and one moderator present to ensure accuracy of the data collected. The Focus Group Guide addressed four key domains: 1) Challenges and Opportunities for HIV Prevention, 2) Identification of HIV Prevention Organizations, 3) Benefits and Challenges to Collaboration, and 4) Reactions to the Idea to Develop an Online STD/HIV Prevention Information System. After each focus group, note-takers listened to the audio recordings and transcribed each focus group, referring to their notes for clarification when necessary. Referring to notes during transcription can improve validity of the results, because it helps transcribers to contextualize the group dynamics, interruptions, and other nonverbal elements of the focus group. (23) Next, observers reviewed the transcripts while listening to the audio recording to check for any discrepancies or inadvertent interpretations of the raw data. The research team discussed any discrepancies until consensus was achieved.

Study analysis. Once the transcriptions were finalized, the research team began the analysis process. First, researchers read each transcript once through with manual coding assigned to indicate statements or paragraphs that related to the four key domains (i.e., Challenges and Opportunities for HIV Prevention, Identification of HIV Prevention

Organizations, Benefits and Challenges to Collaboration, and Reactions to the Idea to Develop an Online STD/HIV Prevention Information System). Interpretative Phenomenological Analysis (IPA), which involves an iterative process of understanding a phenomenon described by study participants in a given context (24) was used to identify themes within and across 7 stakeholder groups. Manual codes were clustered together to form themes. To verify appropriateness of clustering, raw data and coding memos were referenced, aiding in the development of themes from manual codes. (24) Researchers engaged in axial coding and constant comparison to assign the statement(s) to thematic categories. (25) Next, themes which emerged from the stakeholder focus groups were compared with those emerging from the individual interviews. Once these initial themes were manually listed, quotes were identified which exemplified the substance and range of data within each domain. This process culminated in the creation of seven summary files, which contained major themes and quotes from each of the seven stakeholder groups. Finally, emergent themes across the different stakeholder groups were examined, and a tally system was used to explore how often themes emerged in summaries of multiple stakeholder groups. As a final reliability and validity check, the CAC, comprised of representatives from each stakeholder group, was presented with preliminary results and asked to provide feedback on interpretation of findings. The qualitative study findings contributed to the development of measures utilized in the survey study.

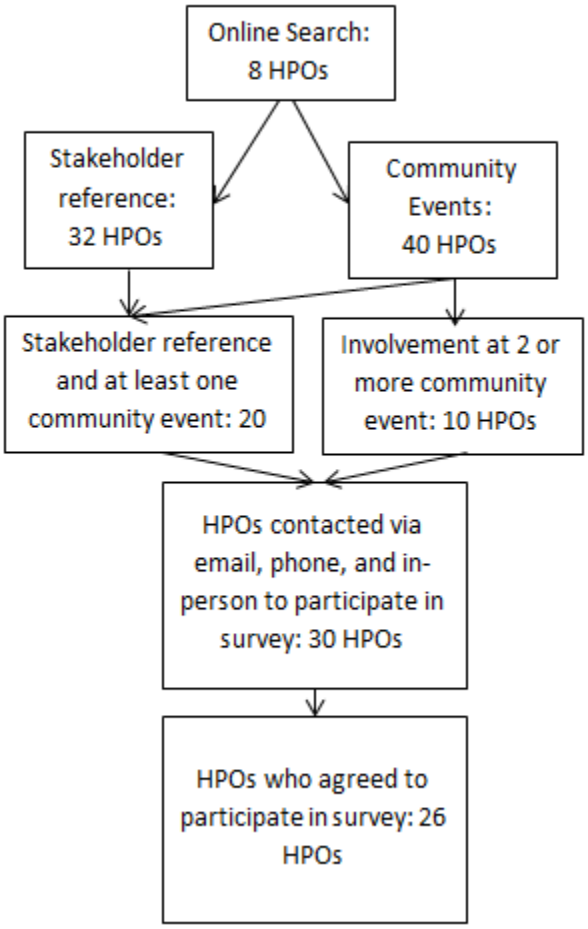
3.3.2 Survey Study: Sampling Frame and Instrument Development.

After an iterative process involving integration of literature reviews on existing measures, researcher development of new measures, and feedback from the CAC, a survey was developed to gain better understanding of themes identified through the

qualitative stakeholder analysis. Concurrent with survey development, a sampling frame was constructed consisting of organizations that either provide, or have the capacity to provide, HIV prevention services to residents living in a high HIV-morbidity suburban area bordering a city with one of the largest HIV epidemics in the country. To identify HPOs for the study, first, a list of HPOs was obtained from the seven stakeholder groups involved in the qualitative study. These stakeholder references culminated in the addition of 32 HPOs to the sampling frame. Next, existing lists of HPOs were identified through community contacts and an online *Google* search. The online *Google* search occurred using key terms, such as "HIV prevention AND [geographic region]" or "condom distribution AND [geographic region]." The 19 HPOs identified through existing lists and online searches were also identified through the other steps. The fourth step, community health event attendance, was heavily guided by our CAC and other engaged community partners. Community event attendance was a crucial step in developing the sampling frame, because: 1) some HPOs lacked a functioning, informative website, 2) some existing organizations had only recently added HIV prevention services, or 3) the HPO was recently funded to provide HIV prevention services to the study community, and had not yet implemented services. Attendance at 13 community events over the course of a year resulted in identification of 40 organizations, some of which were also identified in other steps. The initial sampling frame contained 55 organizations. To identify organizations that were actively serving the community, HPOs were only eligible for the sample if they: a) were identified by stakeholders and by at least one other step in sampling frame development (N=20 HPOs), or b) appeared at two or more community

events (N=10 HPOs). Based on these criteria, the final sample included 30 HPOs. Figure 1 below shows the sampling strategy.

Figure 1: Sampling strategy



3.3.3 <u>Survey Study: Sample Recruitment and Survey Implementation.</u>

Thirty organizations providing HIV prevention services (i.e., testing, counseling, referral, education, and/or condom distribution) to the suburban region were contacted via email and phone by project staff and invited to participate in a one-hour, close-ended, interviewer-assisted, survey about HIV prevention. Executive Directors were invited to complete the survey via interview session over a free lunch or dinner; in 13 cases,

Executive Directors sent Program Directors or those in a similar position to represent them in the interview. In 16 interviews, additional HPO representatives were present to answer survey questions, which was helpful in instances when an interviewee was unsure about service or expertise. Consent was obtained from each participant at all HPOs. Appropriate incentives were discussed with the CAC, and HPOs were offered the option of either a $20 Starbucks gift card or a University coffee mug as a token of appreciation for their time. One experienced member of the research team conducted all interviews, logged the responses and verified them with the respondent before the interview concluded.

3.3.4 Survey Study: Items related to HPO Service and Expertise.

Populations included in the questionnaire are most at-risk for HIV, based on national (13, 26) and local surveillance data (27), as well as feedback from our CAC. *HIV Vulnerable Faith-Affiliated* was added to the survey based on the results of the pre-test with CAC members. This process culminated in 15 vulnerable populations. HIV Prevention Organizations participating in the study were asked to report service to and expertise with the 15 vulnerable populations at-risk for HIV in the study community. An extensive literature review was undertaken to identify survey items measuring organizational capacity to provide services. Several assessments of organizations ask participants about populations served and expertise. (28-30) However, after vetting questions on service and expertise with our CAC, these instruments were revised to be more succinct and to reduce respondent burden. For example, our CAC simplified the response options for the item about population expertise to reduce respondent burden. The resulting response options (i.e., High expertise, Moderate expertise, Low expertise,

and Do not know), were also viewed favorably during the pre-test of the survey instrument.

Service variable. Each organization was asked the following question:

> *"We are interested in learning about the specific types of populations your organization serves. Please respond, "Yes" if you know that your organization serves the population. Respond, "No" if your organization does not serve the population. If you are unaware whether the specific population is receiving services from your organization, please respond, "Do not know."*

In some instances, HPOs responded that they did not know whether a population was receiving their services, and often the reason was that the HPO did not record information about the population. This was interpreted to mean that the HPO was not serving the population to a recognizable extent. While the "Do not know" response was recorded in our data, it was coded as "0" - the same as a response of "*No service*," - in the frequency analysis. Due to high frequency of "Do not know" responses for certain populations, the number of "Do not know" responses has been reported in the Results section and in the Figure 1 table. A "*Yes*" response was coded as "1" (one).

Expertise variable. All 26 HPOs were also asked, "*How would you rate your organization's expertise with each of the following populations*? *High expertise*, *Medium expertise*, *Low expertise*, and *Do not know*. Some executive or program directors interviewed did not have a good sense of their staff's expertise in addressing needs of a specific at-risk population, and responded, "*Do not know.*" It is possible that the term "expertise" may have variable meanings to different individuals. After all the data were

collected, response options were dichotomized distinguishing experts from non-experts for each specific population. A self-report of "*High expertise*" with the population was coded as one (1) and all other responses were coded as zero (0). A response of "Do not know" was treated the same for the expertise and service questions.

3.3.5 Survey Analysis

Throughout the analysis of the survey data, members of the CAC were informed about our process, methods, and results of analyses ensuring that the CAC's perspectives were reflected in the manuscript. One member of the CAC became particularly engaged in analysis, participated in rounds of manuscript revision, and served as a co-author. Frequency analysis was conducted with the Service and Expertise variables, using SPSS version 19, across all 15 at-risk populations. Service and Expertise were analyzed as dichotomous variables, though "Don't know" was given as a third response option. Service was grouped as Yes (meaning this HPO knowingly serves this population) vs. Other Service (meaning this HPO had no indication that they have provided services to the population). Expertise was grouped as High Expertise vs. Other Expertise. The numbers of "Don't Know" responses for each population were tabulated in Figure 1. Data were exported to Microsoft Excel 2010 to create bar graphs for presentation of the data.

3.4 Results

3.4.1 The Mixed Methods Approach

This study incorporates HIV stakeholder focus groups and interviews and a survey of HIV Prevention Organizations. The collection of data was conducted in a sequential manner; thus the survey evolved as the resulting focus group and interview

themes emerged. Therefore, this section presents results from the stakeholder focus groups and interviews first, and then the survey results.

Stakeholder Focus Groups and Interviews. The majority of stakeholder groups identified challenges to HIV prevention related to the population's access to and comfort with existing HIV prevention services. Due to the repetition of theme occurrence across transcripts, codes were developed for s*tigma*, *lack of resources*, and *population*, among others (See Table 2).

Table 2: Qualitative Results

Theme 1	**Theme 2**	**Theme 3**
Stigma	**Lack of Resources**	**Population Challenges**
"Sometimes people do not feel welcome at places and therefore, do not feel comfortable asking for the services they need."	*"Some transgender, minority, or otherwise marginalized are not willing or are uncomfortable going to organizations which are not culturally competent in serving them."*	*"There's a lot of fluidity moving between [jurisdictions] that makes it very challenging to provide a continuum of services to positive and high-risk negative clients. Also, the county is not entirely prepared to deal with an influx of immigrants and non-English speaking individuals. The epidemic is rapidly moving to the county – and there's a lot of catching up to do."*
"Lack of Community Based Organizations in general… not enough to do the work, but particularly in dealing with a population that is stigmatized and already marginalized."	*"There is a need for more community-based organizations who are culturally competent enough to work with the various populations in the County."*	*"We have to take into account how composition of the population has changed and the needs of different subgroups when addressing STD and HIV prevention."*

Survey of HIV Prevention Organizations. Four of the 30 HPOs contacted did not participate in the study for reasons related to eligibility and availability. Hence, 26 HPO interviews were conducted (86.7% participation). Table 3 describes characteristics of participating organizations.

Table 3 Characteristics of Participating HIV Prevention Organizations (HPOs)

"Which of the following categories best describe your organization? Select all that apply."	**Total % (n) N=26**
Non-profit/Charitable/Service-providing	92 (24)
Community Center/Other Community Based Organizations	81 (21)
Medical/Clinic/Hospital	31 (8)
Academic/Educational/Training	23 (6)
Business/Corporation	15 (4)
Religious/Faith-Based Organization	15 (4)
Other (i.e. Community Health Center, Federally Qualified Health Center, & Public Health Institute)	11 (3)
Government/Military/Agencies	4 (1)
Supra-organization (i.e. coalition, alliance, league, consortium, etc.)	4 (1)
Professional Association/Society	0
Personnel	
Less than 10 employees	23 (6)
10-30 employees	31 (8)
31-50 employees	12 (3)
51-100 employees	15 (4)
More than 100 employees	19 (5)
Annual Operating Budget[a]	
Less than 500,000	28 (7)
500,000-one million	12 (3)
Over one million	60 (15)

[a] The denominator is n=25. One organization did not provide its annual operating budget.

Most HPOs were not-for-profit (92%) and/or community-based organizations (81%). Sixty percent of organizations had a budget greater than one million dollars and 28% had

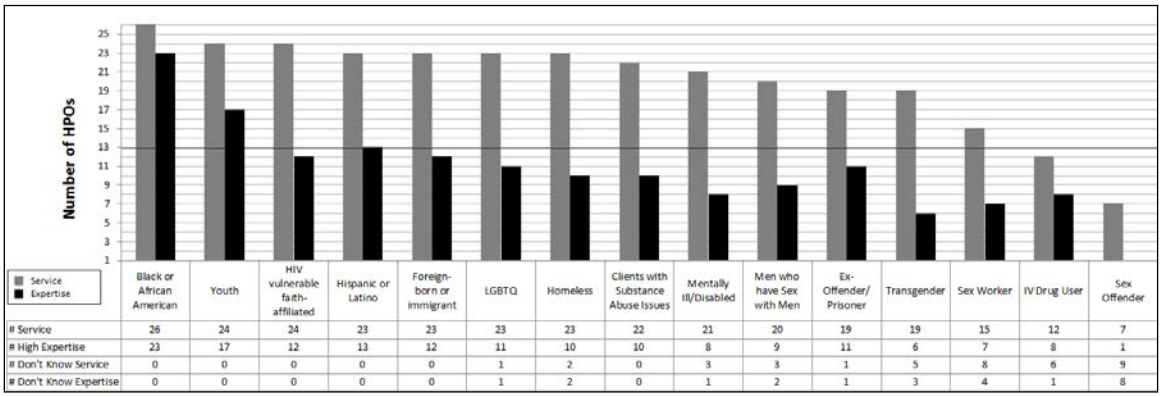
a budget less than $500,000. The number of personnel at each HPO was fairly evenly distributed between categories; most (66%) HPOs had less than 50 employees.

3.4.2 HPO Service to Vulnerable Populations.

The majority of HPOs in the study served nearly every vulnerable population (See Figure 2). There were only two populations that were seen by a minority of HPOs (i.e., less than 50%): *IV Drug Users* and *Sex Offenders.* Figure 2 shows the frequency of HPOs that responded "*Yes"* when asked if they serve each vulnerable population. Ninety to one hundred percent of HPOs in the sample provided service to *Black or African American, Youth,* and *HIV Vulnerable Faith-Affiliated* populations. Eighty to eighty-nine percent of the HPOs in the sample provided service to six of the 15 populations in the sample: *Hispanic or Latino, Foreign-born or Immigrant, LGBTQ, Homeless, Clients with Substance Abuse Issues,* and *Mentally Ill* or *Disabled*. The remaining six populations were *MSM* served by 76.9%, *Ex-offenders/Prisoners* and *Transgender* both served by 73%, *Sex* Workers served by 57.7%, *IV Drug Users* served by 46.7% and *Sex Offenders* served by 26.9% of HPOs.

Nine HPOs (35%) did not know whether they provided service to *Sex Offenders*, eight (31%) did not know if they served *Sex Workers,* six (23%) were uncertain about *IV Drug Users,* and five (19%) did not know whether they provided service to *Transgender* populations. Three or fewer HPOs were unsure about service to *Mentally Ill, MSM, Homeless, Ex-offender,* and *LGBTQ* populations. No HPOs were unsure about providing services to *Black or African American, Youth, Hispanic, HIV Vulnerable Faith-affiliated, Foreign-born or Immigrant,* and *Clients with Substance Abuse Issues*.

Figure 2: Number of HIV Prevention Organizations (HPOs) Reporting Service and High Expertise with Specific Vulnerable Populations (N=26)



	Black or African American	Youth	HIV vulnerable faith-affiliated	Hispanic or Latino	Foreign-born or immigrant	LGBTQ	Homeless	Clients with Substance Abuse Issues	Mentally Ill/Disabled	Men who have Sex with Men	Ex-Offender/ Prisoner	Transgender	Sex Worker	IV Drug User	Sex Offender
# Service	26	24	24	23	23	23	23	22	21	20	19	19	15	12	7
# High Expertise	23	17	12	13	12	11	10	10	8	9	11	6	7	8	1
# Don't Know Service	0	0	0	0	0	1	2	0	3	3	1	5	8	6	9
# Don't Know Expertise	0	0	0	0	0	1	2	0	1	2	1	3	4	1	8

3.4.3 <u>HPO Expertise with Vulnerable Populations.</u>

HIV Prevention Organizations were asked about their expertise in providing services to vulnerable populations. A response of "*high expertise*" indicated participant perception of having capacity to deliver quality care to specific vulnerable populations. Figure 2 shows the frequency of HPOs with self-reported *high expertise* with each vulnerable population. All HPOs in the sample (N=26) are included in the denominator of all percentages. The majority (50% or more) of HPOs had high expertise serving only three of the 15 populations in need of HIV prevention services: *Black or African American*, *Youth*, and *Hispanic or Latino*. Less than 50% of HPOs felt they had *high expertise* serving 12 of the 15 HIV vulnerable populations. For populations served by the majority of HPOs (50% or more), less than half of the HPOs reported *high expertise* with: *HIV Vulnerable Faith-affiliated* (46.2%), *Foreign-born or Immigrant* (46.2%), *LGBTQ* (42.3%), *Ex-Offenders/Prisoners* (42.3%), *Homeless* (38.5%), *Clients with Substance Abuse Issues* (38.5%), *MSM* (34.6%), *Mentally Ill* (30.8%), *Transgender* (23%) and *Sex Worker* (26.9%) populations. While the analysis was most concerned with HPO high

expertise vs. non-high expertise, a response of "Do not know" occurred for *Sex Offenders* (31%), *Sex Workers* (15%), *Transgender* populations (12%) and *MSM* (8%). Less than four percent of HPOs responded that they did not know about expertise with the remaining eleven populations.

Service and Expertise. To gain a better understanding of possible relationships between service and expertise, the two variables were plotted together, showing the frequency of HPOs reporting service and high expertise for each of the 15 populations in the study (as shown in Figure 2).

As is evident from Figure 2, where most HPOs provide service to a population, most also report high expertise. For example, in this metropolitan area, most HPOs serve and self-report high expertise with *Black or African American* and *Youth* populations. On the other end of the spectrum, less than half of the HPOs knowingly serve *IV Drug Users* and *Sex Offenders*, and even fewer reported "*high expertise"* with these populations. Though there appears to be a relationship between service and expertise from the far left and far right ends of the figure, this relationship is less clear in the middle of the graph. Even though the majority of HPOs serve *LGBTQ*, *Homeless*, *Clients with Substance Abuse Issues*, *Mentally Ill/Disabled*, *MSM*, and *Transgender* populations, less than half have self-reported *high expertise* with these populations.

3.5 Discussion

The finding in the organizational survey that there is a misalliance between population expertise and populations served by HIV Prevention Organizations gives credence to the concerns of our Community Advisory Committee and HIV stakeholders as identified through focus groups and interviews. Although the majority of HPOs

provide service to the 15 vulnerable populations identified in the region, many HPOs who serve these populations did not report high expertise with them.

3.5.1 Vulnerable Populations Susceptible to Service-Expertise Mismatch

While nearly 90% of the HPOs sampled provided services to *Foreign-born*, *LGBTQ*, and *Homeless* populations, less than half reported high expertise in serving these populations. Large disparities also exist among *Clients with Substance Abuse Issues*, *Mentally Ill/Disabled*, *MSM*, and *Transgender* populations. These data indicate that although demand for HIV prevention and treatment services for these populations exists, HPOs lack confidence in their ability to meet population-specific needs despite their ongoing provision of services.

3.5.2 Availability of Competent Care for Vulnerable Populations

Access to HIV/AIDS services is associated with better quality of life for PLWH/A.(17,18,21) This study found that all HPOs in the region serve *Black or African American* populations, and most (88.5%) believe they have a high level of expertise with this population. Even though far fewer HPOs had high expertise with *Youth* and *Hispanics or Latinos*, these populations appear to have access to care from HPOs that are confident in their ability to address specific needs of HIV-vulnerable *Youth* and *Hispanic* populations.

3.5.3 Vulnerable Populations Absent from Tracking Systems

HIV Prevention Organizations were most unsure (i.e., responded “Do not know”) about their expertise serving *Sex Offender*, *Sex Worker*, *IV Drug User*, and *Transgender* populations; few HPOs report serving these populations. Our findings suggest a lack of

awareness on the part of several HPOs regarding special services that might be needed for vulnerable populations. Mirroring our findings, the literature suggests difficulties exist in providing services to these populations, and in tracking service to these populations. (18) Capacity building may be necessary to make HPOs more aware of whether they serve vulnerable populations as a first step toward addressing the quality of their services to highly HIV-vulnerable persons.

This case study indicates the need to further explore whether HPOs' expertise with populations vulnerable to HIV is as lacking as it appears to be in this small sample. If confirmed, this identified gap in HIV services could spawn new efforts to improve HPO practice for particular HIV-vulnerable sub-populations.

Future research should identify what factors influence HPOs' perceived expertise - or lack thereof - with populations they knowingly serve. Elsewhere, studies have found that provider judgments regarding perceptions of clients' "immoral" or unreliable behavior may be barriers to care for marginalized groups engaged in socially disapproved risk behaviors.(18) This is especially true in locales where HIV epidemics are concentrated, because PLWH/A sometimes come from marginalized groups, such as *Sex Workers*, *IV Drug Users*, *MSM*, and *Prisoners*.(18) We do not know why HPOs perceive lower levels of expertise with certain populations, or why some do not know about their service to vulnerable populations. However, these findings suggest that HPOs may have reason to earmark resources for addressing expertise with, and service to vulnerable populations. Enhanced attention to vulnerable populations may better address their needs and maintain their engagement in care. Stronger linkages between organizations with

complementary expertise may also be an efficient solution for mismatches between populations and HPO-expertise. (18, 5)

3.5.4 Sharing Results with the Community

Preliminary study findings were shared with the CAC for feedback, and then presented at a local regional conference hosted by a coalition of STD prevention stakeholders. Study participants were invited to the regional conference to hear the results of the research. Conference attendees generally accepted that there are needs related to expertise with vulnerable populations in the region. Audience members discussed the importance of 1) HPOs working together to gain knowledge and awareness of each other's expertise, and 2) strengthening the ability to refer vulnerable patients to expert specialty care.

3.5.5 Limitations

The study focused on two dynamics: services provided and HPOs' perceived expertise. The terms "service" and "expertise" could have complex meanings and have variable interpretations. Therefore, future studies focused only on these factors should ask multiple questions to better understand the nature of HPOs' services and variable levels of confidence when working with vulnerable populations. Future studies may want to use measures of provider cultural competency that already exist (31-35) to obtain more detailed information about HPO services and expertise. Mixed methods approaches to garnering information from vulnerable patients as to their perceptions of care quality specific to each HPO could highlight important gaps in provider cultural competency. (36)

The HPOs in this study represent leading community organizations providing HIV services in a region experiencing a concentrated HIV epidemic. Their generally low perceived expertise with several vulnerable populations suggests the need for capacity building, technical assistance, and/or development of stronger linkages between HPOs with complementary population expertise. This study provides a necessary, but incomplete accounting of HPO services and expertise regarding vulnerable populations in an area highly affected by HIV. It is an important first step in generating awareness that HPOs may still have needs requiring additional resources to: 1) track the vulnerable populations they serve for specific allocation of resources for capacity building; and 2) become more skilled and confident in providing care to these at-risk and marginalized populations. To increase understanding of whether, and to what extent, there exists a gap between HPO service delivery and HPO expertise, future studies should aim to replicate these findings in different geographic areas with increased sample sizes.

3.5.6 Recommendations

HIV service organizations may want to consider multiple structural and programmatic strategies, to increase their competence with vulnerable populations, including: a) reviewing data systems to ensure that care for vulnerable populations (e.g., sex workers, IV drug users, and transgendered individuals) can be tracked and monitored, b) working with providers to help them self-examine and develop their competence with vulnerable populations who they may see least frequently, c) collaborating with other organizations that have competence with these vulnerable populations and developing joint provider training programs, and d) ensuring that appropriate follow-up and referral can be offered to patients with whom providers feel least competent.

The concept of a “medical home” was first defined by the American Academy of Pediatrics in 1992 as a place where patients can receive care that is, “accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective.”(37) The concept has been gaining momentum along with other healthcare reform efforts. (38) HIV infection may occur in conjunction with substance abuse, mental health concerns, social marginalization, and lack of health literacy and resources.(18) Thus, HPOs that can serve as medical homes and offer comprehensive, coordinated care by a multidisciplinary team of providers are needed.(17) Increased coordination and integration of services is especially important for vulnerable populations.(6, 7) The World Health Organization (WHO), CDC, and U.S. Agency for International Development (USAID) all recommend integrating HIV specialists with other care providers(18,39,40). This integration of care is proven to be cost-effective and successful. (17) Our study provides evidence that HPOs may need the affiliation of diverse expertise to address needs of distinct vulnerable populations in order to best address HIV prevention in their communities. Thus, the benefits of the medical home model for PLWH/A could be substantial.

In this study, HPO expertise with sub-populations at-risk for HIV varied. While a majority of HPOs serve and perceive *High Expertise* with a few populations (i.e., *African American or Black, Hispanic/Latino,* and *Youth*), many HPOs lacked *High Expertise* with many HIV-vulnerable populations. The majority of HPOs do not report *High Expertise* in serving 12 of the 15 populations especially vulnerable to HIV and social marginalization. We found that there is less HPO expertise with populations served infrequently by HPOs. Future studies should examine the relationship between vulnerable populations served by

HPOs and the level of competency of the HPOs to serve such populations. Our study suggests that many HPOs need capacity building to improve their expertise in the prevention and care of HIV vulnerable populations.

Study findings support the growing interest in interdisciplinary service integration within and among health services for HIV vulnerable persons as promoted in the medical home concept. Using a systematic, sequential mixed methods study design with a community-based participatory research (CBPR) approach, we learned that the concerns of our community advisors and stakeholders were validated. For example, we heard stakeholders express that, "*Some transgender, minority, or otherwise marginalized are not willing or are uncomfortable going to organizations which are not culturally competent in serving them*"; and found that few HPOs serving the study community report high expertise with the transgender population. Partnership with a Community Advisory Committee, as part of a CBPR approach, proved invaluable in illuminating challenges to HIV prevention, that were borne out in the quantitative research. The community partnership also facilitated interpretation of findings and their implications for current and future programmatic and research efforts. A CBPR approach should be utilized to continue to examine methods for improving service-providers' expertise with vulnerable populations, as this may still be a barrier to HIV prevention.

3.6 Community Policy Brief

Accompaniment to submitted manuscript: **"Investigating community concern regarding HIV Prevention Organizations expertise in serving HIV-vulnerable populations"**

By Denise Bellows, Donna Howard, Brad Boekeloo and Suzanne Randolph

What is the Problem?

- A recent study modeling the future of the HIV epidemic in the United States projected that without rapid scale-up of HIV prevention services, the HIV epidemic will greatly worsen; the status quo will lead to a 29% increase in HIV prevalence over the next ten years.(1)3
- There is an urgent need to examine current HIV service delivery, and identify gaps as well as areas for improvement.
- Interactions of vulnerable populations with the public health system warrants further study, because their needs tend to be more debilitating and life-threatening, they require intensive medical and non-medical services, and there is evidence that this vulnerable population is increasing in size.(12,14,15)

What is the Purpose of this Study /Review?

The purpose of this descriptive study is to understand the extent to which disconnects exist between HIV Prevention Organizations (HPOs) self-rated expertise and their service to vulnerable populations in a metropolitan region experiencing an HIV epidemic.

What are the Findings?

- The HPOs in this study represent community leaders providing HIV services in a region experiencing several concentrated HIV epidemics among vulnerable populations. Their low perceived expertise with several vulnerable populations suggests the need for capacity building, technical assistance, or development of stronger linkages between HPOs with complimentary population expertise.
- This study provides a necessary, but incomplete accounting of HPO service to HIV vulnerable populations and HPO expertise in a community with high HIV morbidity.

Still, this case study marks an important first step in generating awareness that HIV service provider may still have needs requiring additional resources to (1) track the vulnerable populations they serve, and (2) become more confident in providing care to these at-risk and marginalized populations.

Who Should Care Most?

- HIV-prevention researchers.
- HIV/AIDS-focused community-based organizations and service providers
- Agencies who provide funding for HIV prevention and care programs and services
- Health agencies providing HIV prevention and treatment services
- Providers whose clients include vulnerable populations, especially those at-risk for HIV

Recommendations for Action

- Future studies should examine the relationship between low frequency populations and service-provider expertise.
- Development of metrics for provider expertise and service is necessary to improve the way we define HIV vulnerable populations.
- This study supports the growing interest in service integration and the concept of a medical home as a practice solution to engage HIV vulnerable in care.
- Research should continue to examine methods for improving service-provider's expertise with vulnerable populations, as this may still be a barrier to HIV prevention.

3.7 References

1. Hall HI, Green TA, Wolitski RJ, *et al*. Estimated future HIV prevalence, incidence, and potential infections averted in the United States: A multiple scenario analysis. *J. of Acquir. Immune Defic. Syndr*. 2010; 55(2):271-276.

2. Boh WF, Ren Y, Kiesler S, *et al*. Expertise and Collaboration in the Geographically Dispersed Organization. *Organization Science*. 2007; 18(4):595-612.

3. Duran B, Harrison M, Shurley M, *et al*. Tribally-driven HIV/AIDS health services partnerships: Evidence-based meets culture-centered interventions. *J HIV AIDS Soc Serv*. 2010; 9(2): 110-129.

4. Mays GP, Scutchfield DF, Bhandari MW, *et al*. "Understanding the organization of public health delivery systems: an empirical typology." *Milbank Q*. 2010; 88(1): 81-111.

5. Hardina D, Middleton J, Montana S, et al. An Empowering Approach to Managing Social Service Organizations. New York: Springer Publishing; 2007.

6. Markoff LS, Finkelstein N, Kammere N, *et al*. Relational systems change: Implementing a model of change in integrating services for women with substance abuse and mental health disorders and histories of trauma. *J Behav Health Serv Res*. 2005; 32(2):227-240.

7. Muntemba S, Amuah A. Building networks of service-providing institutions: Sourcebook, 2000 July. Available from: http://www.portalmicrofinanzas.org/gm/document-1.9.25991/281.pdf.

8. Shofield JW, Wang L, and Chew P. Culture and Race in Provider-client relationships. *Soc Work Public Health*. 2007; 23(2-3):1-33.

9. Centers for Disease Control and Prevention. High-impact HIV prevention: CDC's approach to reducing HIV infections in the United States, 2013 April. Available from: http://www.cdc.gov/hiv/policies/hip.html.

10. Centers for Disease Control and Prevention. Today's HIV/AIDS Epidemic, 2013 June. Available from: http://www.cdc.gov/nchhstp/newsroom/docs/HIVFactSheets/TodaysEpidemic-508.pdf.

11. Purcell DW, Johnson CH, Lansky A, et al. Estimating the population size of men who have sex with men in the United States to obtain HIV and syphilis rates. *Open AIDS J*. 2012; 6:98-107.

12. Centers for Disease Control and Prevention. Estimated HIV incidence in the United States, 2007-2010. *HIV Surveillance Supplemental Report 2012*; 17(4), 2012. Available from: http://www.cdc.gov/hiv/pdf/statistics_hssr_vol_17_no_4.pdf.

13. Centers for Disease Control and Prevention. *HIV Surveillance Report, 2011*; vol. 23, 2013 February. Available from: http://www.cdc.gov/hiv/pdf/statistics_2011_HIV_Surveillance_Report_vol_23.pdf

14. Millett G, Peterson J, Flores S, et al. A meta-analysis of HIV infection racial disparities among MSM: US. Presented at: *19th Conference on Retroviruses and Opportunistic Infections*, Seattle (WA), March 5-8, 2012.

15. Rhodes T, Wagner K, Strathdee SA, *et al*. Structural violence and structural vulnerability within the risk environment: Theoretical and methodological perspectives for a social epidemiology of HIV risk among injection drug users and sex workers. In: O'Campo P, Dunn, JR, ed. *Rethinking Social Epidemiology: Towards a Science of Change.* Dordrecht, Netherlands: Springer, 2012:205-230.

16. Sumartojo E. Structural factors in HIV prevention: concepts, examples, and implications for research. *AIDS*. 2000; 14:S3-S10.

17. Aday LA. *At Risk in America: The Health and Health Care Needs of Vulnerable Populations in the United States.* 2nd ed. San Francisco: Jossey-Bass, 2003.

18. World Health Organization HIV/AIDS Department. Priority interventions: HIV/AIDS prevention, treatment and care in the health sector. Version 1.2. Geneva, Switzerland: WHO Press, April 2009.

19. Allard S, Roth B. Strained suburbs: The social service challenges of rising suburban poverty. *Metropolitan Opportunity Series*, No. 7, Brookings Institution, 2010 October. Available from: http://www.brookings.edu/research/reports/2010/10/07-suburban-poverty-allard-roth.

20. Wadhwa S, Lavizzo-Mourey R. Tools, methods, and strategies. Do innovative models of health care delivery improve quality of care for selected vulnerable populations? A systematic review. *Jt Comm J Qual Improv*. 1999; 25(8):408-433.

21. Krentz HB, Gill JM. The direct medical costs of late presentation (<350/ mm^3) of HIV infection over a 15-year period. *AIDS Res Treat.* 2012; doi: 10.1155/2012/757135

22. Poindexter, CC. Management successes and struggles for AIDS service organizations. *Adm Soc Work*. 2007; 31(3):5-28.

23. Kidd PS and Parshall MB. Getting the focus and the group: Enhancing Analytical Rigor in Focus Group Research. *Qual Health Res*. 2000; 10:293.

24. Fade S. Using interpretative phenomenological analysis for public health nutrition and dietetic research: a practical guide. *Proceedings of the Nutrition Society*; 2004; 63(4), 647-653.

25. Corbin J, Strauss A. Basics of Qualitative Research. 3rd ed. Los Angeles: Sage; 2008.

26. Centers for Disease Control and Prevention. Who's at-risk for HIV? Centers for Disease Control and Prevention, 2013 April. Available from: http://www.cdc.gov/hiv/risk/index.html.

27. Maryland Department of Health and Mental Hygiene, Center for HIV Surveillance and Epidemiology. Maryland HIV Statistics Overview. Available from: http://phpa.dhmh.maryland.gov/OIDEOR/CHSE/SitePages/statistics.aspx

28. Nu'Man J, King W, Bhalakia, and Criss S. A framework for building organizational capacity integrating planning, monitoring, and evaluation. *J Public Health Manag Pract*. 2007; January (Suppl): S24-S32.

29. Granner ML and Sharpe PA. Evaluating community coalition characteristics and functioning: a summary of measurement tools. *Health Educ Res*. 2004; 19 (5):514-532.

30. Prestby JE and Wandersman A. An empirical exploration of a framework of organizational viability: Maintaining block organizations. *J Appl Behav Sci*. 1985; 21(3):287-305.

31. Kueber R, Maloff B, Penman Y. Blueprint for enhancing cultural competency in the Calgary health region, 2002 April. Available from: http://jonah.crha-health.ab.ca/programs/diversity/diversity_resources/research_publications/blueprint_enhancing_cult_comp.pdf.

32. Campinha-Bacota J. A model and instrument for addressing cultural competence in healthcare. *J Nurs Educ*. 1999; 38(5):203-207.

33. Kagawa-Singer M, Kassim-Lakha S. A strategy to reduce cross-cultural miscommunication and increase the likelihood of improving health outcomes. *Acad Med*. 2003; 78(6):577-587.

34. Mason JL, Williams-Murphy T. Cultural competence self-assessment questionnaire: A manual for users, 1995 August. Available from: http://www.rtc.pdx.edu/PDF/CCSAQ.pdf.

35. Switzer GE, Scholle SH, Johnson BA, *et al*. The client cultural competence inventory: An instrument for assessing cultural competence in behavioral managed care organizations. *J Child Fam Stud*. 1998; 7(4):483-491.

36. Hsueh, CY. Training Needs at Non-Profit Organization [Master's thesis]. Menomonie, WI: University of Wisconsin-Stout; 2008.

37. Sia C, Tonniges TF, Osterhus E, *et al*. History of the Medical Home Concept. *Pediatrics*. 2004; 113(5):1473-1478.

38. Nutting PA, Miller WL, Crabtree BF, *et al*. Initial Lessons from the First National Demonstration Project on Practice Transformation to a Patient-Centered Medical Home. *Ann Fam Med*. 2009; 7(3):254-260.

39. Centers for Disease Control and Prevention. Program collaboration and service integration: Enhancing the prevention and control of HIV/AIDS, viral hepatitis, sexually transmitted diseases, and tuberculosis in the United States. Atlanta (GA): U.S. Department of Health and Human Services, Center for Disease Control and Prevention; 2009.

40. U.S. Agency for International Development (USAID). Family planning/HIV integration: Technical guidance for USAID-supported field programs. Washington DC: USAID; 2003.

Chapter 4 Manuscript 2 Stronger United than Detached: A Descriptive Study of Cross-Jurisdiction Collaboration among HIV Prevention Organizations

This manuscript achieves aim 1 of this dissertation: To examine stakeholder perceptions of HIV prevention challenges and the extent to which there are disconnects between the services available to vulnerable populations.

4.1 Abstract

Objective: Urban HIV epidemics often cross jurisdictional lines, affecting adjacent communities with disparate resources. This awaqstudy describes collaboration between HIV Prevention Organizations (HPOs) and correlates of collaboration across a jurisdictional border.

Methods: Interviewer-assisted surveys were administered to representatives of 26 HPOs to assess perceptions of cross-jurisdictional collaboration, cross-jurisdiction collaborative activity, and cross-jurisdiction grant-writing efficacy.

Results: Jurisdictions differed in the perception that *increased number of clients served* (p=.021) was a benefit to cross-jurisdictional collaboration. Half or more of HPOs in both jurisdictions thought *lack of follow-up* was a barrier. There were jurisdictional differences in whether *lack of incentives (*p=.070) was a barrier to cross-jurisdiction collaboration. For a majority of HPOs, inadequate *staffing* and *resources* prevented cross-jurisdictional grant applications. Cross-jurisdiction grant-writing efficacy was associated with fewer perceived barriers (r = -0.642, p<0.01).

Conclusions: This descriptive study suggests that attention to the benefits and barriers to HPO cross-jurisdictional collaboration is warranted to improve HIV prevention services.

4.2 Introduction

4.2.1 The HIV epidemic

Washington, D.C. and its suburbs share one of the largest HIV epidemics in the United States (CDC HIV Surveillance Report, 2013. Vol. 25, Table 22). The District of Columbia, having the highest incidence of HIV diagnoses in the United States (CDC HIV Surveillance Report, 2013. Vol. 25, Table 18), shares its eastern jurisdictional border with the state of Maryland. High incidence and prevalence rates of HIV infection are also observed in the neighboring Maryland suburbs. In fact, one zip code in Prince George's County, Maryland (on the DC border) is six miles from the U.S. Capital and has among the highest number and rate of living HIV cases in the county; one out of every sixty residents is living with HIV; an HIV prevalence of 1,667.3 per 100,000 (Prince George's County HIV/AIDS Epidemiological Profile, 2011; Creekmur, 2014). Other HIV epidemics spanning state jurisdictional borders, for example: New York City, Hudson County, NJ, and Fairfield County, CT; Hartford County, CT and Hampden County, MA; Yuma County, AZ, Imperial County, CA, and Mexico; and many parts of the south east U.S. (i.e. state borders between North and South Carolina, Georgia, Florida, Alabama, Mississippi, and Louisiana) (AIDSVu, 2010).

4.2.2 Community reaction to the HIV epidemic

The HIV epidemic has provided impetus for the emergence of organizations– often grassroots and community-based – providing specialty services to address the needs

of people living with HIV (PLWH) and prevent the on-going spread of the epidemic. Organizations involved in HIV prevention services include public agencies, clinics, faith-based organizations and other non-profits, many of whom focus their efforts on high-risk groups facing social injustices, such as racism and classism (Bellows, Howard, Boekeloo, Randolph. Progress in Community Health Partnerships in press 2016; Aday, 2003). Many of these HIV Prevention Organizations (HPOs) emerged in urban areas where HIV epidemics originated in the U.S. In recent years, however, HIV epidemics have spread into suburban and rural neighborhoods. Indeed, the Washington D.C. metropolitan area provides a case example of this cross-jurisdictional spread of the HIV epidemic (DeRenzis and Rivlin 2007, Allard and Roth 2010, Wallace and Wallace, 1995). Movement of the HIV epidemic from urban to suburban areas occurred as the perceived urgency surrounding HIV/AIDS has dissipated (Valdiserri, 2004; Aldoory, Bellows, Boekeloo, Randolph, In Press 2015) and deaths from AIDS waned to historic lows due to new effective treatments. The unfortunate consequence is that the movement of the epidemic into the suburbs has not garnered much political attention (Valdiserri, 2004; Aldoory, Bellows, Boekeloo, Randolph, In Press 2015).

At the 2012 International AIDS Conference, Health and Human Services Secretary Sebelius stated the following:

> *"We are reminded over and over again that we need a collective response to turn the tide against HIV/AIDS. That's why we're making a new effort to reach out to community-based organizations, businesses, foundations, non-governmental organizations, faith-based organizations*

and other partners to ask how we can work together. These public-private partnerships will help make a difference in people's lives," (HHS Press Office, 2012).

A collective collaborative response is necessary to ensure greater progress is made towards ending the HIV epidemic. Gaining an understanding of the challenges and successes of HIV-related collaborations is needed to facilitate these efforts.

4.2.3 Collaboration among HIV prevention organizations

Public health delivery systems vary widely in their organization and scope of activity; however, comprehensive and highly integrated models of public health are needed to address HIV (Mays, Scutchfield, Bhandari, and Smith, 2010). High levels of integration between all components of a comprehensive public health delivery system require high levels of collaboration (CDC, 2009). Collaboration can be defined as any relationship between two entities. A relationship between two entities may occur at different levels of integration, on a continuum from low integration to high integration (Gajda, 2004). For example, low integration is limited to communicating information or exploring interests; high integration is more likely to include planning and program execution to achieve a mutual goal (Gajda, 2004) and ongoing patterns of interaction (Lawrence, Hardy & Philips, 2002). Ongoing interaction between organizations often leads to common understanding and common practice, which can foster the kind of change that is credited to collaborative efforts (Lawrence, Hardy & Philips, 2002). Organizational collaboration for HIV prevention is also needed because care for PLWH, and prevention for at-risk populations, depends on services that address multiple complex individual, interpersonal, and social factors. Today's public service organizations must

function with greater interdependence and interconnectedness as the scope of health challenges broaden and the pace necessary to address challenges quickens (McGuire and Silvia, 2010). Hence, addressing the HIV epidemic requires coordinated effort between various health service organizations and social service organizations. Ultimately, collaboration that is ongoing and highly integrated has the greatest potential to lead to community-wide change (Lawrence, Hardy, & Philips, 2002; CDC, 2009).

4.2.4 HIV prevention organization collaboration across jurisdictional borders

The cross-jurisdictional component of collaboration among HIV prevention organizations (HPOs) has not been emphasized as a significant aspect of collaborative relationships. Still, these relationships are common and are different from collaborative relationships not involving a jurisdictional border. For example, one study found that in emergency response systems, organizations which function at a higher capacity have managers who collaborate more often and more effectively across jurisdictional boundaries (McGuire and Silvia, 2010). Another study of cross-jurisdiction arrangements for health services in the European Union (EU) concluded that research should attempt to understand cross-jurisdictional efforts to increase efficiency, quality, and access to services (Busse, Worz, Foubister, Mossialos, Berman, 2006). The study identified major hurdles to healthcare access created by borders and arrangements between jurisdictions, including: cost differences for healthcare by jurisdiction; capacity of healthcare facilities to serve the population in a timely manner; and, choice of providers for patients. As an initial effort to understand cross-jurisdictional collaborations, this study explores current collaborative efforts between health service

providers – specifically those providing HIV prevention services – and their perspectives about cross-jurisdictional collaboration for HIV prevention.

Some cross-jurisdictional relationships among organizations have been successful, even in the face of border-related challenges. The Four Corners American Indian Circle of Services Collaborative is a Navajo Nation-wide collaborative across the jurisdictional border between New Mexico and Arizona, which worked to increase HIV prevention efforts and improve care for PLWH (Duran, Harrison, Shurley, et al., 2013). The cross-jurisdiction collaborative pooled resources from all jurisdictions to plan, implement, and evaluate an HIV prevention and treatment intervention across the multi-jurisdictional region. This resulted in comprehensive, coordinated, and continuous care to HIV-positive individuals, their families, and their communities (Duran, Harrison, Shurley, et al., 2013). While successful, it was unclear the extent to which organizational factors fostered cross-jurisdictional collaboration for HIV prevention.

This present study of the Washington, D.C. / Maryland border region explores factors associated with HPOs' cross-jurisdictional collaboration for HIV prevention and productivity of organizational collaboration efforts. It compares organizations on each side of the D.C. / Maryland jurisdictional border in terms of: 1) perceived benefits and barriers to cross-jurisdiction collaboration; 2) self-efficacy for cross-jurisdiction grant writing; 3) number of HIV-related cross-jurisdiction project collaborations; and, 4) number of collaborations on cross-jurisdiction grant applications. Relationships among these 4 dynamics are also examined. Findings elucidate issues that encourage or discourage cross-jurisdictional border organizational collaboration for HIV prevention.

4.3 Methods

4.3.1 Mixed Methods, Community-Based Approach

An exploratory, sequential, mixed methods research design using a community-based participatory approach was implemented prior to study data collection. This process began with the convening of a Community Advisory Committee (CAC) to identify research priorities and provide feedback on all activities. All CAC participants represented either Washington, D.C., or bordering jurisdictions in Maryland. The established CAC deemed it necessary to first conduct a qualitative, exploratory study with seven stakeholder groups: (1) State and (2) County representatives, (3) Community-Based Organizations, (4) Medical Personnel, (5) Funding agencies, (6) University students, and (7) Community residents. Focus group and interview participants were asked to discuss challenges and opportunities for HIV prevention, perceptions related to inter-organizational collaboration, and other related topics. Analysis of qualitative data resulted in the identification of several themes. Specifically, all seven stakeholder groups identified challenges to HIV prevention in the region related to communication structures and coordination between stakeholders and service entities. Also, the Prince George's County, Maryland/DC jurisdictional border was identified as a major point of differentiation between organizations and HIV services. For example, differences in number of services, types of services and common practices of service providers in each jurisdiction were discussed by participants. Collaboration as a potential solution to HIV prevention challenges was also discussed by all seven stakeholder groups. These qualitative findings contributed to the development of survey measures utilized in the current study. A more detailed accounting of the research approach prior to survey

development can be found in articles previously published by the authors (Aldoory L, Bellows D, Boekeloo B, Randolph SM, 2015; Bellows D, Boekeloo B, Howard D, Randolph SM, in press 2016).

4.3.2 Survey Development

After an iterative process involving integration of literature reviews on existing measures, researcher development of measures, and feedback from the CAC, a survey was developed to gain better understanding of themes identified through the aforementioned qualitative stakeholder analysis. The result was a list of survey items reflecting barriers and benefits to collaboration across a jurisdictional border. The items were reviewed by the CAC to determine whether or not the community found the items to be relevant to their experiences with cross-jurisdiction collaboration for HIV prevention. The measure was then pre-tested with representatives of 3 HPOs, who offered small modifications to some of the items. The final survey and data collection protocol were approved by the Institutional Review Board of the researcher's academic institution.

4.3.3 Sampling Frame Development

Occurring concurrently with survey development, a sampling frame was created consisting of organizations that either provide, or have the capacity to provide, HIV prevention services (i.e. condom distribution, education, and testing) to residents living in the high HIV-morbidity Maryland suburban area bordering DC. In developing this sampling frame, it was determined that there was no single inclusive listing of HIV Prevention Organizations (HPOs) serving this area. Thus, the research team developed a 4-step strategy to identify HIV prevention organizations (HPOs) for the study. First, a list

of HPOs was obtained from the 7 stakeholder groups involved in the qualitative study. Next, existing lists of HPOs were identified through community contacts and word of mouth. Third, an online Google search of organizations was conducted using key terms, such as "HIV prevention AND [geographic region]" or "condom distribution AND [geographic region]." The fourth step involved one year of participation in community health events occurring in the region to further identify relevant organizations. Community event attendance was a crucial step in developing the sampling frame, because some HPOs did not have a website that was searchable online, and other existing organizations were either newly funded to serve the study community or recently added STD/HIV prevention services. The resulting sampling frame contained 55 HPOs. To narrow the list to organizations that were actively serving the community, HPOs that were not identified in at least two of the four search strategies were excluded. Based on these criteria, the final sample included 30 HPOs; 15 urban and 15 suburban.

4.3.4 Sample Recruitment and Survey Implementation

Consent was obtained from each interview participant in the study and the study protocol was approved by the Institutional Review Board of the researcher's academic institution. Thirty organizations providing HIV prevention services to the suburban D.C. region were contacted via email and phone by project staff and invited to participate in a one-hour, close-ended, interviewer-assisted, face-to-face survey about HIV prevention and cross-jurisdiction collaboration. Executive Directors from 30 HPOs were invited to complete the survey over a complimentary lunch or dinner; however, in 13 cases, executives sent Program Directors or those in a similar position to represent them. In 16 interviews (53%), more than one HPO representative was present to answer survey

questions about the organization. Three participants requested administration of the interview over the phone. Each HPO was given a choice of either a $20 Starbucks gift card or a coffee mug as a token of appreciation for their time. One trained member of the research team, experienced with HPOs in the region, conducted all interviews. Interview responses were recorded and verified by the respondent before the interview concluded. Ultimately, 26 interviews were conducted. De-identified data were entered into a database in SPSS version 19 for analysis.

4.3.5 Variables examined in the survey

Cross-jurisdiction Collaboration Benefits and Barriers. To assess HPOs' perceived benefits and barriers to cross-jurisdictional collaboration, participants were asked the following question: "*Please describe the extent to which each of the following is a [benefit/barrier] for your organization to work across the Washington, D.C./Prince George's County border*." Participants were asked to respond by selecting one of the following response options: "*Not at all*," "*Very little*," "*Somewhat*," "*A lot*." The Benefits scale included the following 9 items: *potential for funding, more efficient use of funding, improved quality of services, expanded reach to populations, potential to increase number of clients served, increased credibility, ability to show funders that organization has support of others, ability to address equitable funding allocation, and ability to influence decision-makers*. The Barriers scale included the following 9 items: *competition for funding, time and energy, mission and services, trust, past experiences, follow-up, leadership, incentives to collaboration and issues discussing sensitive topics*. For both the benefits and barriers scales, a composite score was created by summing the scores for each item and dividing by the total number of items (n =9). This Benefits scale

yielded marginally acceptable reliability among the study sample of HIV Prevention Organizations (Cronbach's alpha of 0.68). The Barriers scale had stronger reliability (Cronbach's alpha of 0.81).

Collaborations. HPOs participating in the survey were asked to list all current collaborative partners on the other side of the jurisdictional border. Specifically, HPOs were to list collaborations which resulted in provision of services, events, or programs to residents in both jurisdictions. The number of collaborators listed by each organization was counted and the total became the new variable "*number of current collaborators*." HPOs were also asked to list any partnerships established to jointly seek grant funding. The number of partners listed by each organization was counted and the total became the new variable "*number of grant partners*." Organizations mentioned in response to both questions were summed to create a "*Total cross-jurisdiction collaborations*" variable. Organizations were only counted one time in the "*Total cross-jurisdiction collaborations*" variable.

Cross-jurisdiction Grant Efficacy. During the focus groups and interviews preceding survey development, HIV prevention stakeholders discussed lack of resources for organization collaboration across the Maryland/DC border. To better understand that concern, a measure was created to determine the extent to which HPOs believed they had the resources and support to seek cross-jurisdiction grant funding with another organization. Under the survey section, "*Grant-seeking collaboration capacity of organization*," each HPO was asked, "*To what extent do you agree with the following*? 1) *my organization's staff has the skills needed to seek cross-jurisdictional grant funding with another organization*, 2) *my organization's staff has a track record of success and*

experience necessary to seek cross-jurisdictional grant funding with another organization, 3) *there are enough personnel at my organization to seek cross-jurisdictional grant funding with another organization*, 4) *my organization fully supports seeking cross-jurisdictional grant funds with another organization*, 5) *my organization's stakeholder support seeking cross-jurisdictional grant funds with another organization*, 6) *my organization's collaborators support seeking cross-jurisdictional grant funds with another organization*, and 7) *my organization has the resources needed (i.e., time, equipment, computer software, etc.) to seek cross-jurisdictional grant funding with another organization*. Response options included: *strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree*. A composite score was created by summing the scores for each item and dividing by the total number of items (n=7 items). The cross-jurisdiction grant-efficacy scale had strong reliability in the study sample of HIV Prevention Organizations (Cronbach's alpha of 0.71).

4.3.6 Analysis

Descriptive statistics were calculated for characteristics of HPOs in the sample, and each variable in the study (i.e., perceived benefits and barriers to collaboration, number of collaborators, and perceived efficacy in cross-jurisdictional grant-writing). A non-parametric correlation matrix (using Spearman's Rank) was conducted with the following variables: *number of grant-writing collaborations*, *grant efficacy* and *perception of benefits and barriers to cross-jurisdiction*. Sum and mean composites were created for perceived benefits, perceived barriers and grant efficacy scales. The Mann-Whitney U test was used to compare jurisdictional differences in individual items in each measure (i.e., *perceived benefits scale, perceived barriers scale, and grant efficacy*

scale), and differences in the composite score for each measure. Cronbach's alpha was used to create a measure of internal consistency for each scale. Significance was designated as $p<.10$ given the small sample size and exploratory nature of the study. SPSS version 19 was used to conduct all analyses.

4.4 Results

After multiple attempts to survey all 30 HPOs in the study sample over a 20 week period, the interviewer-assisted surveys were conducted with leaders of 26 HIV Prevention Organizations (HPOs); 14 urban HPOs and 12 suburban HPOs. The four non-participant HPOs cited the following reasons for non-participation: 1) ineligibility, i.e., because they were not direct service providers (n=2); 2) lack of approval from a partner organization (n=1); 3) lack of availability of the appropriate respondent (n=1). Hence, 26 HPO interviews were conducted (86.7% participation). Table 4.4.1 describes characteristics of participating organizations.

Table 4.4.1: Characteristics of HIV Prevention Organizations (HPOs) in the Sample

Which of the following categories best describe your organization? Select all that apply.	**Urban % (n) N=14**	**Suburb % (n) N=12**	**Total % (n) N=26**
Non-profit/Charitable/Service-providing	100 (14)	83 (10)	92 (24)
Community Center/ Other Community Based Organization	86 (12)	75 (9)	81 (21)
Medical/Clinic/Hospital	43 (6)	17 (2)	31 (8)
Academic/ Educational/Training	29 (4)	17 (2)	23 (6)
Business/ Corporation	21 (3)	8 (1)	15 (4)
Religious/Faith-Based Organization	7 (1)	25 (3)	15 (4)
Other (i.e. Community Health Center, FQHC, & Public Health Institute)	21 (3)	0	11 (3)
Government/Military/Agencies	0	8 (1)	4 (1)
Supra-organization (i.e. coalition, alliance, league, consortium, etc.)	7 (1)	0	4 (1)
Professional Association/Society	0	0	0
Staff/Personnel	**Urban % (n)**	**Suburb % (n)**	**Total % (n)**
Less than 10 employees	14 (2)	33 (4)	23 (6)
10-30 employees	36 (5)	25 (3)	31 (8)
30-50 employees	14 (2)	8 (1)	12 (3)
50-100 employees	14 (2)	17 (2)	15 (4)
More than 100 employees	21 (3)	17 (2)	19 (5)
Annual Operating Budget	**Urban % (n)***	**Suburb % (n)**	**Total % (n)**
Less than 500,000	15 (2)*	42 (5)	28 (7)
500,000-one million	0	25 (3)	12 (3)
Over one million	85 (11)*	33 (4)	60 (15)

*n=13. One participant did not provide annual operating budget.

HPOs on both sides of the jurisdictional border were predominately not-for-profit (92%) and/or community-based organizations (81%) (Table 4.4.1). The small sample size precluded valid statistical comparisons, but by absolute percentage, more organizations in the urban sub-sample identified as medical/clinic/hospital (43%) than the suburban sample (17%). For HPO resources, 85% of urban organizations had a budget

greater than 1 million dollars compared to 33% of suburban organizations. Likewise, 42% of suburban organizations had a budget less than $500,000 compared to only 15% of urban organizations.

4.4.1 Benefits

The majority of organizations (i.e., 50% or more) on each side of the jurisdictional border agreed on several specific benefits to cross-jurisdiction collaboration (See Figure 4.4.1). "*Service improvement*," "*potential for more funding*," and "*efficient use of funding*," were recognized as benefits to collaboration by the majority of both urban and suburban organizations. In the urban jurisdiction, the majority of HPOs perceived "*increase number of clients served*," and "*greater credibility with the community"* as benefits to collaboration; whereas only a minority of HPOs in the suburban region perceived these factors to be benefits to collaboration (Figure 4.4.1). In the suburban region "*equitable funding allocation"* was considered a major benefit of collaboration by more than 50% of the organizations sampled; however only 35% of urban HPOs viewed "*equitable funding allocation"* as a benefit to cross-jurisdiction collaboration (Figure 4.4.1). Less than 50% of HPOs rated "*Ability to influence decision-makers*," "*reaching special populations*," and "*demonstrated support"* as major benefits to cross-jurisdictional collaboration. Jurisdictional differences in perceived benefits to cross-jurisdictional collaboration were compared statistically using the Mann-Whitney U (aka Wilcoxon Rank Sum) test. There was no statistically significant difference ($p=0.876$; *Mann-Whitney U*=81, n1=12 n2=14) between jurisdictions when comparing the composite benefits score for urban versus suburban organizations. However, when each item in the benefits scale was compared by jurisdiction, a statistically significant

difference was found for "*increased number of clients served*," (p=.021; *Mann-Whitney U*=49, n1=12 n2=14). As depicted in Figure 4.4.1 below, D.C. HPOs perceive "*increased number of clients served*" was a potential benefit to cross-jurisdictional collaboration with suburban organizations; however, far fewer HPOs in the suburban jurisdiction perceive this as a benefit to collaboration with urban HPOs.

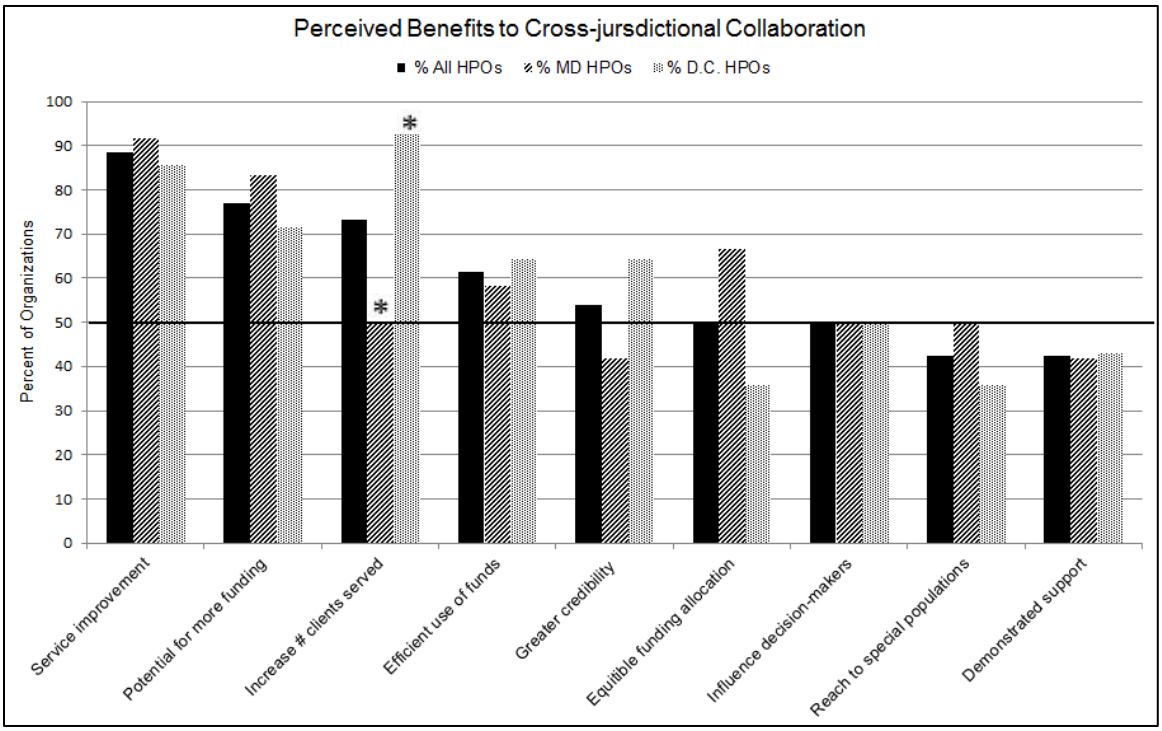


Figure 4.4.1. This figure portrays the percent of HPOs in the sample (vertical axis) who believe that each factor (horizontal axis) was a major benefit to HPO collaboration across jurisdictional borders for HIV prevention. The solid horizontal bar at the 50% measure delineates factors influencing the majority vs. minority of HPOs in the sample. *Mann-Whitney U (aka Wilcoxon Rank Sum) test was use to statistically compare the differences between D.C. and Maryland HPOs. There was a statistically significant difference between perception of "*increased number of clients served*" as a benefit to cross-jurisdictional collaboration (p=.021; *Mann-Whitney U* = 49, n_1=12 n_2=14).

4.4.2 <u>Barriers</u>

Of all the barriers identified in the Perceived Barriers to Cross-jurisdictional Collaboration scale, there was only one item most HPOs in each jurisdiction identified as a barrier: "*lack of follow-up*." *Lack of follow-up* was perceived as a barrier by 50% of

Maryland HPOs and 57% of D.C. HPOs (Figure 4.4.2). In the sub-sample of suburban organizations, the majority (58%) identified "*lack of time and energy*" as a barrier to cross-jurisdiction collaboration; however, this was only viewed as a major barrier by 36% of urban HPOs (Figure 4.4.2). In the sub-sample of urban organizations, 43% of HPOs identified both "*competition for funding*," and "*negative prior experiences*" as major barriers to cross-jurisdictional collaboration. Another urban-suburban difference in perceived barriers to cross-jurisdiction collaboration was in "*lack of incentive*." None of the suburban organization believed "*lack of incentive*" was a barrier; however, 36% of urban organizations reported this as a major barrier to cross-jurisdiction collaboration (Figure 4.4.2). The Mann-Whitney U (aka Wilcoxon Rank Sum) test was used to statistically compare jurisdictional differences in perceived barriers to cross-jurisdictional collaboration. There was no statistically significant difference (p=.553; *Mann-Whitey U*=72.5, n_1=12 n_2=14) between jurisdictions when comparing the composite barriers score for urban versus suburban organizations; nor were there statistically significant differences when each item in the barriers scale was compared by jurisdiction. However, though not statistically significant, there was a sizeable difference in "*lack of incentives*," (p=.070; Mann-Whitney U=50, n_1=12 n_2=14). While 35.7% of D.C. HPOs perceive "*lack of incentives*" as a barrier to cross-jurisdictional collaboration with suburban organizations, there were no HPOs in the suburban jurisdiction who perceived "*lack of incentives*" as a major barrier to cross-jurisdictional collaboration (Figure 4.4.2).

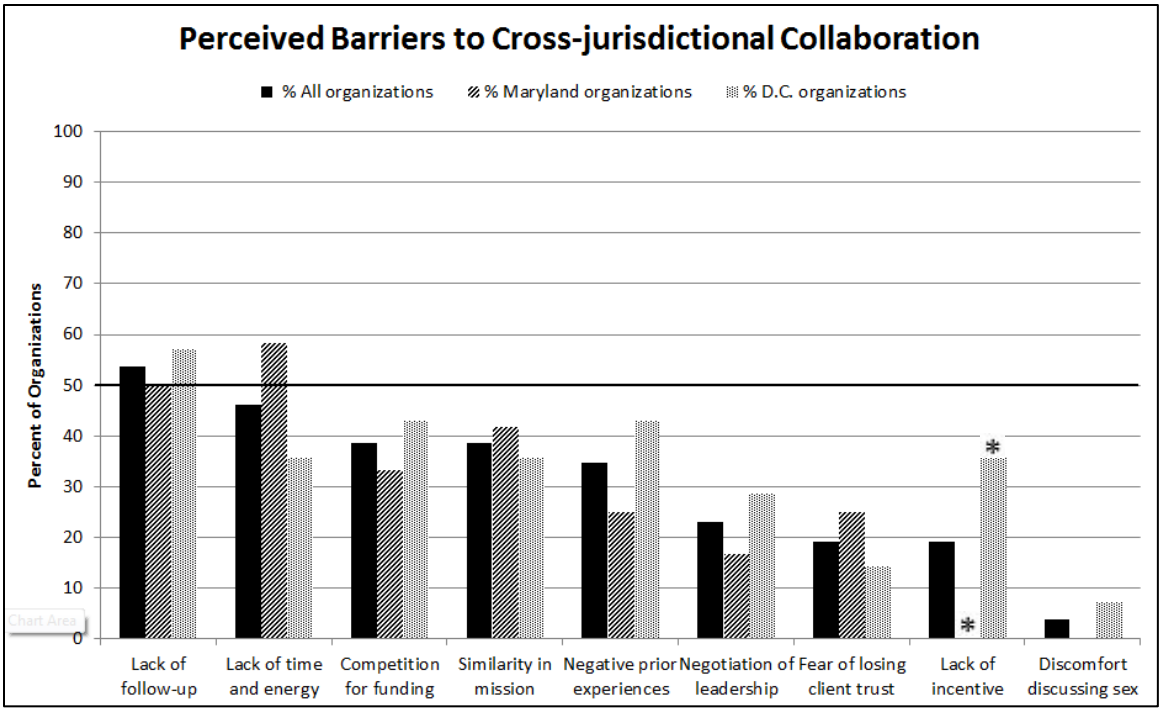


Figure 4.4.2. This figure portrays the percent of HPOs in the sample (vertical axis) who believe that each factor (horizontal axis) was a major barrier to HPO collaboration across jurisdictional borders for HIV prevention. The solid (black) horizontal bar at the 50% measure delineates factors influencing the majority vs. minority of HPOs in the sample. The difference between perception of "*lack of incentives*" as a barrier to cross-jurisdictional collaboration in each jurisdiction was marginally statistically significant ($p=.070$; *Mann-Whitney U* = 50, $n_1=12$ $n_2=14$).

4.4.3 <u>Cross-jurisdiction Grant Efficacy</u>

Most HPOs in the sample (92%) either agreed or strongly agreed that their "*organization supports*" cross-jurisdiction grant-seeking activity and the same percent of the sample also agreed or strongly agreed that their staff have the "*skills needed*" for this cross-jurisdiction grant-writing (Figure 4.4.3). HPOs were least confident in having "*enough staff*" (50%) and "*enough resources*" (46%) to seek cross-jurisdiction grant funding with another organization (Figure 4.4.3). The Mann Whitney U test of difference was computed for each item and the composite score to determine if there were significant differences between grant-efficacy on each side of the jurisdictional border.

The mean score for perceived efficacy for cross-jurisdictional grant-writing was not statistically different by jurisdiction (p=.624; Mann-Whitney U=74.5, n1=12 n2=14), and there was no specific item on the scale that was significantly different by jurisdiction. The greatest difference in perceived efficacy between jurisdictions was found in the item, "*support of collaborators*" (p=.384; Mann-Whitney U=69, n1=12 n2=14).

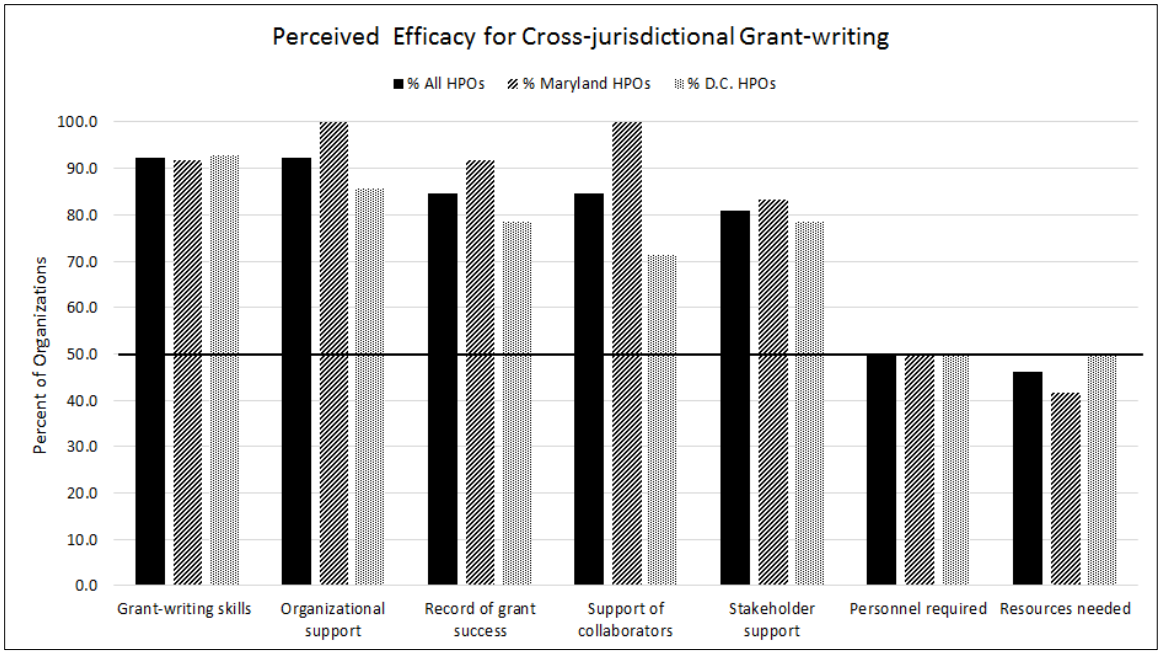


Figure 4.4.3. This figure portrays the percent of HPOs in the sample (vertical axis) who believe that each factor (horizontal axis) affects their efficacy in pursuing grant funding for HIV prevention with an organization across the jurisdictional border. The solid (black) horizontal bar at the 50% measure delineates factors influencing the majority vs. minority of HPOs in the sample. There were no statistically significant differences between D.C. and Maryland HPOs.

4.4.4 <u>Collaborations</u>

Overall, 89 instances of cross-jurisdiction collaboration were mentioned by HPOs in the sample, with the average number of collaborations being 3.42 (s.d.=2.16) per HPO. Jurisdictional differences in frequency of collaborations were minimal; 46 collaborations were reported in the urban jurisdiction ($\bar{x}$ =3.29, s.d.=2.46), and 43 collaborations were reported in the suburban jurisdiction ($\bar{x}$ =3.58, s.d.=1.75). Instances of cross-

jurisdictional collaboration mentioned by HPOs did not differ significantly in the urban versus suburban jurisdiction (p=.484; *Mann-Whitney U*=70.5, n1=12 n2=14).

4.4.5 Correlation analysis

Spearman's rank was used to compare the following variables: mean perceived barriers to cross-jurisdictional collaboration, mean perceived benefits to cross-jurisdictional collaboration, mean cross-jurisdictional grant efficacy, and number of organizations included in cross-jurisdictional collaborations for events, services, programs, or grant seeking activities. The correlation matrix is shown below:

Table 4.4.2: Results of nonparametric correlation analysis

Spearman's Rho (N=26)	Mean cross-jurisdictional grant efficacy score		Mean benefits to cross jurisdictional collaboration		Mean barriers to cross-jurisdictional collaboration		Number of cross-jurisdictional grant partnerships		Total number of cross-jurisdictional collaborators	
	Corr. Coef.	Sig.	Corr. Coef.	Sig.	Corr. Coef.	Sig.	Corr. Coef.	Sig.	Corr. Coef.	Sig.
Mean cross-jurisdictional grant efficacy score	1.00	.	-.085	.680	**-.642****	**.000**	**.339***	**.090**	.098	.634
Mean benefits to cross jurisdictional collaboration			1.00	.	.100	.628	.116	.573	-.151	.460
Mean barriers to cross-jurisdictional collaboration					1.00	.	.077	.710	-.044	.832
Number of cross-jurisdictional grant partnerships							1.00	.	**.461***	**.018**

Total number of cross-jurisdictional collaborators					1.00 .

* Spearman's Rho Correlation is significant at p<0.10 (2-tailed)
**Spearman's Rho Correlation is significant at p<0.001 level (2-tailed)

The results indicate that three correlations were statistically significant. Cross-jurisdiction grant-writing efficacy was associated with fewer perceived barriers (r = -0.642, p<0.01) and greater number of past grant collaborations (r = 0.34, p<0.09). Also, the total number of cross-jurisdictional collaborations was associated with the number of cross-jurisdictional grant partnerships (r = 0.46, p<0.02) as would be expected given the overlap in the variables.

4.5 Discussion and Implications

4.5.1 Service Systems Encouraging Cross-jurisdiction Collaboration

Half or more of participating organizations on both sides of the jurisdictional border agreed that benefits for cross-jurisdictional collaboration include *service improvement*, *potential for more funding*, and *efficient use of funds*. This finding could be of value to agencies that provide HIV prevention funding. If HPOs already perceive that collaboration with organizations across the jurisdictional border could improve their services to the public and allow them to use funds more efficiently, it may be worthwhile for funding agencies to provide grant opportunities to HPOs who collaborate across jurisdictional borders. In recent years, there have been funding announcements which require collaboration between multiple organizations; however, few specifically require collaboration between multiple jurisdictions.

A surprising finding of the study, there were significantly more HPOs in the urban jurisdiction who perceived an *increased number of clients served* as a benefit of cross jurisdictional collaboration than in the suburban jurisdiction. The urban jurisdiction has a larger population, so it is not clear why increasing the number of clients served would be a greater benefit in the urban than the suburban organizations. As the urban region has been experiencing increasing gentrification, where their poor and vulnerable populations have been forced to move into the suburban region, it is possible that urban HPOs see cross-jurisdictional collaboration as a means to serve these migrating populations and expand their catchment areas. On the other hand, the suburban HPOs have been on the receiving end of the effects of gentrification and have seen an increase in their number of clients, often without an increase in their access to funding, capacity, and resources. This could also explain why *equitable allocation of funding* was perceived as a benefit to cross-jurisdictional collaboration for the majority of suburban HPOs, but only a minority of urban HPOs.

4.5.2 Overcoming Barriers to Cross-Jurisdictional Collaboration

Both urban and suburban HPOs perceived that *lack of follow-up* was a major barrier to cross-jurisdictional collaboration. This barrier was identified in numerous stakeholder focus groups and interviews during the formative research process. In the stakeholder interviews and focus groups, *lack of follow-up* was described as situations where organizations collaborate on an event and after the event occurs, they do not follow-up with a report on event outcomes, so the success of the event cannot be properly evaluated (Aldoory, Bellows, Boekeloo, Randolph In Press 2015).

Lack of time and energy was perceived differently in each jurisdiction. The majority of suburban HPOs perceived this to be a major barrier to cross-jurisdictional collaboration; while a minority of urban HPOs saw this as a major barrier. This finding was not surprising when comparing operating budgets. While over 4/5 HPOs in the urban jurisdiction have an annual operating budget of one million or more dollars, only 1/3 of HPOs in the suburban jurisdiction have this large of a budget. With limited financial resources to provide services to a needy population, it is reasonable that the amount of time and energy required to pursue a collaborative relationship may be a deterrent, especially if the return on that investment is not a guarantee and is dependent on a variety of other uncertain factors (Aldoory, Bellows, Boekeloo, Randolph In Press 2015).

The jurisdictional difference in *lack of incentives* as a perceived barrier to cross-jurisdictional collaboration was statistically significant; over a third of urban HPOs reported this as a barrier and no suburban HPOs viewed this as a barrier. Perhaps the urban HPOs have more resources and; therefore, project that they may have to contribute more than they will gain in the relationship.

The other barrier perceived by a majority of urban HPOs is *competition for funding*. Unfortunately, many funding opportunities are based on competitions between HPO applications. Furthermore, even when collaboration is sought by funders, joint applications may require various agreements about power and control over resources and this may pose additional issues related to competition. Funding mechanisms may, therefore, require systematic restructuring if competition between HPOs is to be minimized.

Despite *competition for funding* being a barrier, in both the urban and suburban jurisdiction the majority of HPOs were confident that their *organization would support* cross-jurisdictional grant-writing. They were also confident that their HPO had the *skills needed* for cross-jurisdictional grant-writing. However, the majority of both urban and suburban HPOs were not confident about whether they have *enough staff* and *enough resources* to pursue cross-jurisdictional grant writing. Once again, this suggests a struggle regarding resources for cross-jurisdictional collaboration.

Finally, perceived barriers to cross-jurisdictional to collaboration were statistically correlated with cross-jurisdiction grant-efficacy which was marginally correlated with number of cross-jurisdictional grant collaborations. Efforts to decrease the perceived barriers may increase cross-jurisdictional grant-writing efficacy. Also, addressing some barriers to collaboration may be important in encouraging cross-jurisdiction grant partnerships. In particular, low perceived resources and staff may be a deterrent to urban/suburban partnerships for grant-seeking. Additionally, as this relationship would be hypothesized, the findings tend to validate the efficacy and barriers measures.

4.5.3 Study limitations

One limitation of this study is the small sample size. The implementation of this survey relied on securing one-on-one time with executives at very busy organizations. Initially, prior to the interviewer-assisted face-to-face survey method, the researchers attempted an online survey, but received no response. In speaking with some executives at HPOs while attending community events, the researchers learned that most executives

preferred a face-to-face meeting. Due to the small sample size, nonparametric statistics were used to compare jurisdictional differences. It is possible that had the study included more HPOs in the region and the sample size were larger, there would have been more significant differences identified between jurisdictions. However, the smaller case study approach had several strengths, including a richer set of organizational data, which was sensitive in some cases. This data could not have been obtained without a preceding relationship-building process, wherein trust was developed between the researcher and the organization.

While some items from existing measures were used, the researchers created new measures to reflect benefits and barriers identified by stakeholders during focus groups and interviews. The measures were then pre-tested and vetted through community advisory groups. Although the benefits, barriers and grant-efficacy multi-item scale measures all had good internal consistency, their validity could not be determined.

Identifying the sampling frame presented challenges. We learned that the HPOs in the region change on an annual basis, as most of them rely on grant funding which is not guaranteed year-to-year. Therefore, though we communicated with HPOs who were most active and most well-known in the communities they serve, new HPOs emerged with new funding and were not captured in the study, and some HPOs included in the study subsequently lost funding changing their role in the community. Hence, the HPOs surveyed were from an ever changing landscape of HPOs and may not represent HPOs in the area at another point in time. Despite this challenging reality, the sampling process utilized in this research included the breadth of organizations with the potential to provide services in the medically underserved border region at a specific period in time.

4.5.4 Recommendations for future research

Future studies should follow-up on several findings of this exploratory study. For one, the survey measures produced for this study were created through a community-based participatory research process and, though they have good internal consistency, they need to be evaluated for validity. Also, new funding mechanisms should be examined to determine whether they decrease barriers to cross jurisdictional collaboration, and decrease competition rather than increase HPO competition. Finally, similar explorations of HPO collaborations across other jurisdiction borders are warranted to determine whether the barriers to coordinated HIV prevention efforts found in this study are commonly encountered elsewhere.

4.5.5 Conclusions

In conclusion, this exploratory study suggests that although HPOs perceive multiple benefits to cross-jurisdictional collaboration, they also perceive barrier barriers that may impede cross-jurisdictional efforts and hence further examination of the barriers to cross-jurisdictional collaboration is warranted to enhance the effectiveness of HIV prevention services.

4.6 References

Aldoory L, Bellows D, Boekeloo B, Randolph S. (2015). Exploring use of relationship management theory for cross-border relationships to build capacity in HIV prevention. *Journal of Community Psychology*,43(6):687-700.

Bellows D, Boekeloo B, Howard D, Randolph SM. (In Press 2016). HIV Prevention Organizations' expertise in serving HIV-vulnerable populations: Investigating community concerns, *Progress in Community Health Partnerships*.

CDC HIV Surveillance Report, 2011. Vol. 23, Table 19. Available at: http://www.cdc.gov/hiv/library/reports/surveillance/2011/surveillance_report_vol_23.html

"Secretary Sebelius announces innovative public-private partnerships to turn the tide together in the fight against HIV/AIDS." HHS Press Office, News Release, July 22, 2012. Available at: http://www.hhs.gov/news

Brooke DeRenzis and Alice M. Rivlin. (2007). A Pathway to the Middle Class: Migration and Demographic Change in Prince George's County. The Brookings Institution, Greater Washington Research Program. April 2007.

Allard SW and Roth B. (2010). Strained Suburbs: The Social Service Challenges of Rising Suburban Poverty. Brookings Institution, Metropolitan Opportunity Series.

Wallace R, Wallace D. (1995). U.S. apartheid and the spread of AIDS to the suburbs: a multi-city analysis of the political economy of spatial epidemic threshold. Soc Sci Med. 1995 August. 41(3):333-45.

Rebecca Gajda. (2004). Utilizing Collaboration Theory to Evaluate Strategic Alliances. American Journal of Evaluation. Vol 25: 65.

Valdiserri, RO. (2004). Mapping the roots of HIV/AIDS complacency: implications for program and policy development. *AIDS Education and Prevention*, 16(5):426–439.

Lawrence TB, Hardy C, and Phillips N. (2002). Institutional Effects of Inter-organizational Collaboration: The emergence of proto-institutions. The Academy of Management Journal. Vol 45 (1): 281-290.

Tschannen, Dana. (2004). The effect of individual characteristics on perceptions of collaboration in the work environment. MedSurg Nursing – October 2004. Vol 13(5): 312-320.

Peterson NL. (1991). Interagency collaboration under Part H: The key to comprehensive, multidisciplinary, coordinated infant/toddler intervention services. *Journal of Early Intervention.* Vol.15(1):89-105.

Prince George's County HIV/AIDS Epidemiological Profile, Fourth Quarter 2011, Infectious Disease Bureau, Prevention and Health Promotion Administration, DHMH http://phpa.dhmh.maryland.gov/OIDEOR/CHSE/SitePages/statistics.aspx;

Creekmur P. Prince George's County Health Department, Health Report 2014 http://www.princegeorgescountymd.gov/sites/Health/ContactUs/Publications/Documents/2014%20health%20report%20v4-08-14%20no%20blank%20pages.pdf

AIDSVu.org. Persons Living with an HIV or AIDS Diagnosis, 2010, Accessed Feb 22, 2015

Amabile TM, Patterson C, Mueller J, Wojcik T, Odomirok PW, Marsh M, and Kramer S. (2001). Academic-Practitioner Collaboration in Management Research: A Case of Cross-Profession Collaboration. The Academy of Management Journal. Vol 44(2): 418-431.

Pinto RM. (2012). What Makes or Breaks Provider-Researcher Collaborations in HIV Research? A Mixed Method Analysis of Providers' Willingness to Partner. *Health Education & Behavior*, Vol. 40(2): 223–230.

Centers for Disease Control and Prevention (CDC). Program Collaboration and Service Integration: Enhancing the Prevention and Control of HIV/AIDS, Viral Hepatitis, Sexually Transmitted Diseases, and Tuberculosis in the United States. Atlanta (GA): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2009.

McGuire M, Silvia C. (2010). The Effect of Problem Severity, Managerial and Organizational Capacity, and Agency Structure on Intergovernmental Collaboration: Evidence from Local Emergency Management. Public Administration Review, 279-288.

Durham C. (2010). Collaboration Incentives: Local Government Experiences with the American Recovery and Reinvestment Act. Thesis submitted to University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree, Master of Public Administration.

Mays GP, Scutchfield FD, Bhandari MW, and Smith SA. (2010). Understanding the Organization of Public Health Delivery Systems: An Empirical Typology. The Milbank Quarterly: A multidisciplinary Journal of Population Health and Health Policy, Vol. 88(1):81-111.

Duran B, Harrison M, Shurley M, Foley K, Morris P, Davidson-Stroh L, Iralu J, Jiang Y, and Andrasik MP. (2013). Tribally-Driven HIV/AIDS Health Service Partnerships: Evidence-based meets culture-centered interventions. Journal of HIV/AIDS and Social Services, Vol. 9(2): 110-129.

Busse R, Worz M, Foubister T, Mossialos E, and Berman P. (2006). Mapping Health Services Access: National and Cross-jurisdiction Issues (Health ACCESS). Report Health and Consumer Protection Directorate General, European Commission.

Chapter 5 Manuscript 3: Exploring the utility of the Health Services Utilization Model to explain organizational barriers to coordinated HIV prevention across jurisdictional borders

5.1 Abstract

Background: Public Health lacks a clear theoretical framework for thoroughly understanding and articulating organizational challenges to coordination of HIV prevention services in metropolitan areas that cross jurisdictional borders. The constructs of the Health Service Utilization (HSU) framework – Accessibility, Acceptability, Accountability, and Availability – may provide a useful framework for addressing these challenges. The purpose of this study was to use a rigorous, thorough methodology, the Matrix Method of Literature Review (MMLR), to validate the Health Services Utilization Model (HSUM) for its comprehensiveness and utility in explaining organizational barriers to coordinated HIV prevention across jurisdictional borders.

Method: In this study, the terms borders, HIV, and health services, were entered into the PubMed MeSH database to build a list of controlled vocabulary terms (i.e., MeSH terms). These MeSH terms, in combination with the four constructs of the HSUM were entered into the PubMed search database to identify articles related to each component of the HSUM in the context of the research question. Searching continued until duplicate articles began to appear in each search and searches identified fewer than 20 articles. The search filters "in humans" and "in the past 5 years" were added to limit search results. The results from each search were reviewed and the resulting articles were abstracted into an MS Excel database where they were ranked for relevance to the study topic. First tier

articles included a discussion of HIV, borders, and health services; Second tier articles included a discussion of borders and health services; Third tier articles discussed HIV and health services, and fourth tier articles discussed HIV and borders. Abstracts of all ranked articles were reviewed for their relevance to organizational barriers to coordinated HIV prevention across jurisdictional borders. First tier articles were reviewed in their entirety and used to derive new HSUM construct definitions. The new HSUM construct definitions based on MMLR were compared with pre-existing definitions of HSUM constructs.

Results: After articles within each HSUM construct were ranked, among first tier articles – which all discuss HIV, borders, and health services: 5 related to availability; 5 related to accountability; 4 related to accessibility; and 0 discussed acceptability. Since no first tier articles were available for the construct, acceptability, second tier articles were reviewed for their ability to validate or add to the definition of the acceptability construct; no additional sub-constructs were identified. The Health Service Utilization Model captured all of the organizational barriers to cross-jurisdictional collaboration for HIV prevention. The matrix method of literature review process used to validate the HSUM resulted in the addition of 14 sub-constructs, which built upon the existing model and operationalized the model for use in addressing organizational barriers to HIV prevention across jurisdictional borders. In addition, the method for testing the model (i.e., the MMLR) clarified strengths and limitations of the literature on HIV, borders, and health services.

Conclusion: The HSUM provides a framework for identifying potential barriers to organizational coordination across jurisdictional borders for HIV prevention. Identifying

these challenges/barriers can be helpful in developing solutions to coordination in HIV prevention service in metropolitan areas that cross jurisdictional borders. Future studies should analyze the gaps in the literature related to HIV, borders, and health services, which emerged from this study.

5.2 Introduction

5.2.1 HIV, Borders, and Health Services

The 2012 Institute of Medicine (IOM) report, *For the Public's Health: Investing in a Healthier Future*, makes several recommendations pointing to the need for increased study of how place and public health infrastructure influence the health of the nation. The report provided the following general recommendations for public health system improvement: 1) There is a need for greater coordination between funded health agencies; 2) Public health should have a clinical core; 3) Public health should collaborate to develop evidence-based strategies to address population health needs; 4) Federal agencies should design and implement funding to incentivize coordination among public health stakeholders; 5) Collaboration is needed across agencies and organizations (stakeholders) to develop a model for better tracking of funding and related outputs/outcomes across agencies. Additionally, one of the primary goals of the National HIV/AIDS Strategy (NHAS) released by the United States government in 2010 is to achieve a more coordinated national response to the HIV epidemic through increasing coordination of programs between federal agencies and local governments; including improved monitoring and reporting on progress towards national goals. This study examines challenges and opportunities related to public health coordination and

collaboration as it relates to HIV prevention stakeholders in the midst of an epidemic straddling a jurisdictional border.

A critical component of HIV care and treatment is the continuum of care from home to healthcare facilities throughout the duration of infection (WHO, 2002). A community's ability to link with outside services and institutions to create an infrastructure of continuous care for the patient is an important determinant of its capacity for addressing HIV and other health issues (WHO, 2002). WHO recommends strategic linkages, partnership development and collaboration between health and social services and the communities they serve in order to provide the best possible care to the community. More recently, the Centers for Disease Control and Prevention issued a White Paper articulating specific frameworks for collaboration and service integration between public health infectious disease services, including: surveillance, training, laboratory services, partner services, behavioral interventions, and health education messaging (CDC, 2009). Creating community-health system partnerships can be difficult when the HIV community spans a jurisdictional border. A jurisdictional border is defined as the geographic boundary separating the areas of two governing authorities. Also, jurisdictional border migration may impact the collaborative interactions between health services and the community. For example, community residents migrating across the border to obtain health services in the nearest proximity may not be permitted to receive certain types of care if their residence is in the former jurisdiction. Organizations themselves may face a dilemma about whether or not to provide services to individuals from another jurisdiction, especially if their funding is jurisdiction specific (e.g., organizations funded by local tax revenue.) Thus, there is a need for research to identify

and address the HIV prevention and treatment barriers posed by jurisdictional border (Conference on Advancing the National HIV/AIDS Strategy in Greater Washington, 2012).

5.2.2 Health Services Utilization Model

In a 2010 study to determine whether there were access to care barriers and facilitators specific to the U.S.-Mexico border region, researchers held focus groups at community clinics on each side of the jurisdictional border (Zuniga, Blanco, Palinkas, Strathdee, & Gifford, 2006). Researchers asked participants about four dimensions of human and social service utilization: 1) Availability of services, 2) Accessibility of services, 3) Acceptability of services, and 4) Accountability. These four dimensions have been discussed as dimensions of health service delivery as early as 1985, by Stefl and Prosperi; however, with slight differences from the Zuniga, et al. model referenced above. Blank, et al., identified the exact same four dimensions as obstacles to effective mental health service delivery in rural areas (1995). In 2000, the United Nations Committee on Economic, Social, and Cultural Rights adopted a General Comment on the Right to Health, which proclaimed that the right to health contains four elements: availability, accessibility, acceptability, and quality of services (United Nations Economic and Social Council, Committee on Economic, Social, and Cultural Rights, 2000). The General Comment (General Comment No. 14) states that these four elements are the underlying determinants of health, which should be assured to all people. This decision by the United Nations was part of a new rights-based approach to health policies and programs. More recently, in 2010 Sophia Gruskin, editor of the American Journal of

Public Health, and colleagues, specifically pointed to availability, accessibility, acceptability and quality as key barriers to sexual and reproductive health (Gruskin, Bogecho, & Ferguson, 2010).

As evidence from the literature, this study of HSUM will build on previous research to understand whether and how jurisdictional borders pose barriers to coordinated HIV prevention in each of these four dimensions. This study will also explore whether additional border-related barriers to coordinated public health exist, which are not already considered in HSUM.

5.3 Methods

For the purpose of this analysis, the following definitions will be used for availability, accessibility, acceptability, and accountability:

1. **Availability**: The existence of public health and healthcare facilities in sufficient quantity; however, it specifies that "sufficient quantity" is relative to the region. Services which should be in sufficient quantity to provide health to the public include safe drinking water, sanitation facilities, hospitals, clinics, trained medical and professional personnel receiving competitive salaries, and essential drugs (United Nations Economic and Social Council, Committee on Economic, Social, and Cultural Rights, 2000). Zuniga, et al. also describes availability of services as the existence of services, and has operationalized the definition as, "Are services available in the geographic area?" (Zuniga, et al., 2006). This operationalization of availability will be used for this study.

2. **Accessibility**: The U.N. General Comment No. 14 defines accessibility as having four overlapping dimensions: "(i) Non-discrimination: Health facilities, goods and services must be accessible to all, especially those most vulnerable; (ii) Physical

accessibility: Health facilities, goods and services must be within safe physical reach to all, especially vulnerable or marginalized groups. This includes adequate access to buildings for persons with disabilities; (iii) Economic accessibility (i.e. Affordability): Health facilities, goods and services must be affordable for all, meaning that payment for services is based on the principle of equity, ensuring that poorer households are not disproportionately burdened with health expenses as compared to richer households; and (iv) Information Accessibility: Includes the right to seek, receive, and impart information and ideas concerning health issues, but does not impair the right to have personal health data treated with confidentiality." These components require special attention to the most vulnerable and affected populations, and are relevant for the field of sexual health (Gruskin, Bogecho, & Ferguson, 2010). Zuniga and colleagues defined availability simply as "service convenience or affordability," in their study of healthcare service utilization in the U.S.-Mexico border region. In addition to the thorough definition provided by the U.N., and confirmed by the Gruskin article, the operationalization of accessibility to services as used by Zuniga and colleagues considers factors related to a border region, and therefore, will be very useful for this study. Client transportation and literacy level of materials provided by health service providers will also be considered in the definition of accessibility, as was done in the Zuniga study.

3. **Acceptability**: The U.N. General Comment No. 14 defines accessibility as, "all health facilities, goods and services must be respectful of medical ethics and culturally appropriate, as well as designed to respect confidentiality and improve the health status of those concerned." Moreover, health facilities, goods and services must be, "sensitive to sex and life-cycle requirements," (Gruskin, Bogecho, & Ferguson, 2010). The 2006 study

by Zuniga and colleagues defined acceptability as, “how congruent services are with client expectations (cultural),” and operationalized this definition as including consideration of social expectations, language needs, client comfort, as well as addressing potential stigmas.

4. **Accountability**: Quality is defined as, “requiring goods and services to be scientifically and medically appropriate and of good quality; specifically, skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water and adequate sanitation (United Nations Economic and Social Council, Committee on Economic, Social, and Cultural Rights, 2000). While quality is important, it does not describe the mechanism for assuring quality is provided in all goods and services. For this reason, accountability seems to be a more useful component of the model. Gruskin and colleagues defines *accountability* as “mechanisms at local, national, regional, and international levels to monitor compliance and support governments in fulfilling their human rights obligations to their populations, which impact on health and development,” (Gruskin, Bogecho, & Ferguson, 2010). The Zuniga models discusses accountability as accountability of services to clients and to the community, which is a much better fit for this discussion of jurisdictional border. According to Zuniga and colleagues, accountability refers to service system responsiveness to clients and community. This does not negate, but rather builds on the previously mentioned definitions. The study by Zuniga and colleagues specifically mentions the necessity of mechanisms for consumers to participate in service decision-making or to provide feedback on services they receive.

5.3.1 Matrix Method of Literature Review

The Matrix Method of Literature Review (Gerrard, 2011; Goldman & Schmalz, 2004) is utilized in this study to systematically examine *organizational barriers to coordinated HIV prevention across jurisdictional borders* and to determine whether constructs of the Health Service Utilization Model encompass organizational barriers. The Matrix Method of Literature Review (MMLR) was specifically designed for reviews of the health sciences literature, and provides a precise, systematic strategy for reading, analyzing and summarizing scholarly material (Gerrard, 2011). The MMLR is defined as a structure and process for systematically reviewing the literature and a system for bringing order out of the chaos of too much information spread across too many places (Goldman & Schmalz, 2004). There are several benefits of using the MMLR over other methods of literature review. First, the MMLR makes it easier to identify gaps and predominant themes in the literature, because of the visual format provided by the matrix. Second, MMLR's clear format for tracking search results allows for method replication. Lastly, the organization of the literature elucidates where authors or groups of authors agree, disagree, and build on each other's work.

The Matrix Method of Literature Reviews was used to determine whether or not the literature validates the health service utilization model (HSUM), and whether there is evidence that HSUM is an appropriate model for addressing organizational challenges to coordinated HIV prevention across jurisdictional borders.

There are four main components of the MMLR: 1) Paper trail, 2) Document File, 3) Review Matrix, and 4) Synthesis. The paper trail was used to document the search process and all relevant materials identified. For example, lists of keywords, key sources,

electronic bibliographic databases and related searches, internet searches, and other notes were included in the paper trail. The document file is a folder where each of the downloaded files, PDF's or links to articles are kept and organized. For this study, a reference manager (i.e., Zotero) was also used to organize references and link references to PDF documents. The most unique component of MMLR is the Review Matrix, giving MMLR its name. The Review Matrix consists of rows, columns and cells, as in a basic Microsoft Excel spreadsheet. This spreadsheet was used to abstract information from each piece of literature identified in the MMLR process. The columns of the matrix were used to categorize the article in various ways. The first few columns of the matrix document article citation information and the specific search criteria which produced the resulting article. The next set of column headings included each construct of the Health Services Utilization Model, the terms used to rank articles (i.e., borders, HIV, and health services) and other terms related to the research question, including: *organization, organizational barrier, border-related barrier, coordinated HIV prevention, border as a barrier to health, border-based disparity, border-based discrimination, cultural differences, economic differences, state/jurisdictional border, coordination/cooperation, collaboration on specific issues, barriers/challenges,* and *metropolitan/urban area*. Each row of the matrix represents a specific piece of literature (e.g. journal article, study, book, government report, dissertation, etc.). Each cell in the matrix includes column-related notes about the piece of literature in the row. Finally, the synthesis is the part of the MMLR where the review of the literature is written based on the abstraction of articles in the matrix. In this study, the synthesis consisted of the derivative of HSUM construct definitions from articles reviewed in the matrix, and comparing that definition to the

HSUM definition which existed before this study. Also, in this study, articles were ranked for their relevance to the research question before they were reviewed more thoroughly. First tier articles included a discussion of HIV, borders, and health services; Second tier articles included a discussion of borders and health services; Third tier articles discussed HIV and health services, and Fourth tier articles discussed HIV and borders. Abstracts of all ranked articles were reviewed for their relevance to organizational barriers to coordinated HIV prevention across jurisdictional borders. . First tier articles were reviewed in their entirety and used to derive new HSUM construct definitions. In summary, the four step process of conducting the MMLR includes: (1) Identify search terms and search methods, (2) Select and organize documents for review, (3) Abstract the research literature, and (4) Synthesis of the literature from the matrix.

5.3.2 Identifying search terms and search methods

Starting with the terms *border, HIV,* and *health services,* an initial list of key terms was identified during a review of major references related to organizational barriers to coordinated HIV prevention across jurisdictional borders (Table 5.3.1). These terms included HIV prevention, coordination of HIV prevention, and organizational barriers to healthcare across jurisdictional borders and the constructs of the theoretical framework (Availability, Accessibility, Acceptability, Accountability, and Health Service Utilization) were also used to derive keywords. Literature reviews on the concept of border conducted prior to this study identified Border Theory and several terms related to border, which were included to thoroughly explore any literature related to jurisdictional border.

Table 5.3.1 Key words searched in MeSH database

Theoretical Framework	Research Question	Border Theory
Health Service Utilization	HIV/AIDS Prevention	State border
Model	Agency	Jurisdictional border
Availability	Organization	Border
Accessibility	Coordination	Boundary
Acceptability	Coordinated HIV prevention	Borderline
Accountability	Coordinated	Borders as a barrier to health
	Cooperation	Borders as a barrier to HIV prevention
	Collaboration	Border-based discrimination and disparity
	Barriers	Cultural differences
	Challenges	Economic differences
	Metropolitan area	Social differences
	Urban area	Trust
	Organizational barrier	
	Border-related barrier	

Once the initial list of keywords was created (table 5.3.1), these keywords were entered into the PubMed MeSH terms database[1] between September 21, 2014 and October 5, 2014 to identify controlled vocabulary words. Controlled vocabulary words are arrangements of words and phrases used to index search database content and for PubMed, these terms and phrases are specific to public health and medical fields. Appendix E, "Results of Keyword searches in MeSH Terms Database," provides detail on the MeSH terms identified and used in the search process. The table in Appendix E has two columns; the first column (on the left) shows the term entered into the MeSH database and the second column (on the right) displays the definition of those terms according to PubMed. In instances where multiple MeSH terms resulted from a keyword search, all terms are listed in the first column and only those terms relevant to the study were defined in the second column. For example, entering the key word "availability" into the MeSH database resulted in 23 terms:

Biological availability, nutritive value, ***health services accessibility****, supply and distribution, sequestering agents,* ***healthcare disparities****, Hypoxia-Inducible Factor 1, Vascular Endothelial Growth Factor Receptor-1, Iron Regulatory Protein 1, Serotonin Syndrome, Haemophilus influenzae type b, Receptors, Glucagon,* ***health manpower****,* ***Community Health Workers****, PhoQ protein, E coli, NPC2 protein, Drosophila, Pap31 protein, Bartonella bacilliformis, PhoP protein, E coli, ccm1 protein, Chlamydomonas reinhardtii, iron response regulator protein, Bacteria, rosiglitazone, U93385, Inzolen.*

Of the 23 terms related to "availability" in the MeSH database, only four terms (those in bold above) were related to coordination of HIV prevention services across jurisdictional borders. Therefore, for the keyword "availability" only these four additional MeSH terms were defined in the second column, and considered in creation of search queries of the PubMed database.

Appendix E, "Results of Keyword searches in MeSH Terms Database," served as the basis for the PubMed search for articles related to the research question and the components of the HSUM. The National Library of Medicine's PubMed database was selected as the search database for this study because the purpose of this study is to explore the potential for the Health Service Utilization Model framework to be utilized by public health service organizations, and PubMed contains over 24 million citations in

biomedical, life sciences, behavioral sciences, and health literature. Also, PubMed only indexes articles which meet standards for scientific objectivity.

Once the complete list of MeSH terms was collected from the keyword search, a new document, the "*E-bibliographic Database Document*," (Appendix F), was created to track how each piece of literature was found and reduce the risk of repeated or redundant searches. The research question relates to the social and political climate, which changes with time. Therefore, for searches which resulted in more than 100 articles, a filter was added to the search, "in the past 5 years" to identify the most recent literature on a topic. If a search pulled up few articles without this 5-year filter, the filter was not added. For all of the keywords and controlled vocabulary words mentioned, searches started with broad terms and more specific terms were added with each search. When searches of the key terms and combinations of key terms and MeSH terms began to bring up duplicate articles, fewer than 5 articles, or articles that were not relevant, the searching for that term was completed. After exploring PubMed searches with all keywords and MeSH terms, the articles resulting from each search were entered into the MS Excel Literature Matrix for further review. Using a combination of MeSH terms and key words, this process resulted in 132 searches conducted between October 23, 2014 and October 26, 2014.

5.3.3 Select and organize documents for review

Decisions on whether to pursue articles resulting from certain keyword searches were based on the volume of articles appearing in a search result. For example, if an initial search of the term "Health Service Utilization Model" produced 8,371 articles, usually a review of the first few pages of article titles found that many titles did not appear to be relevant to the research topic. This was recorded in the *E-bibliographic*

Database Document, as was each of the 132 searches conducted, and then additional terms were added to the search query until searches resulted in fewer article, but more articles relevant to the research topic. Therefore, a new search was conducted by adding a key word found through the MeSH database and related to the research question, in attempt to focus the search result on the research question and obtain the articles most relevant to the research question. The process of adding key words and MeSH terms continued until searches resulted in no articles, or until duplicate articles resulted from the search. Often when adding terms related to HIV or borders to other MeSH terms, no articles resulted in the search. During this iterative search process, it was also discovered that using the PubMed search filter "in humans" was helpful in eliminating articles on other biological sciences topics not relevant to the study of health services. For example studies about HIV in laboratory animals would not be relevant to this study, so using the filter term "in humans" excluded those studies from the search results. In addition, older articles which surfaced in initial searches were often no longer relevant because the state of health services have since evolved. Therefore, searches were limited to articles published in the past 5 years. If no articles were available for a search in the past 5 years, this filter was completely removed to determine whether or not any articles were available related to the key terms. Of the 132 searches conducted, 58 searches resulted in 20 or fewer articles, and contained titles most relevant to the research question. Details of the specific searches conducted and the results of the searches can be found in the E-*bibliographic database* document (Appendix F).

By copying the syntax used for the initial search query (See Appendix F), and pasting it into PubMed, the results from each of the 58 searches were re-produced. There

were 285 articles resulting from the 58 searches and article citation was saved into the reference manager, Zotero. After the citations were saved in Zotero, the citations were entered into the Literature Review Matrix in MS Excel to be ranked and reviewed. Electronic copies of articles were downloaded and stored in the "Document Folder." These documents were also linked to the citation in the reference manager, Zotero. Of the 285 articles, 25 of the articles were duplicates, triplicates or quintuplicate; appearing in multiple search results. Only one copy of each of the 25 duplicate articles was kept in the database with a note indicating that the article also appeared in other searches; the other copies of the duplicate articles were removed from the database. While most duplicates surfaced when searching under the same category (e.g., Accountability, Accessibility, Acceptability, etc.) there were five instances of duplicates, where articles surfaced in different search categories. The removal of duplicate articles resulted in 260 articles.

5.3.4 Description of the Matrix and ranking of articles

Each article in the Literature Matrix had its own line in the database, and the columns in the database indicate a reference number for the article and the search criteria which produced the article. Each row also contains the category of the search, the specific search terms and search syntax used to produce the article, and then the article reference information (i.e., author(s), title, journal, and year). The literature matrix has columns for abstracting the article purpose, methods and key findings, to help in ranking the articles. Column headers related to the research questions were used to rank the articles. Articles which relate to the following pre-determined categories were ranked as follows:

First tier = Articles which include discussion of borders, HIV, and health services

Second tier = Articles which include discussion of borders and health services

Third tier = Articles which include discussion of HIV and health services.

Fourth tier = Articles which include discussion of HIV and borders

Article title and journal were reviewed to fill in "Yes or No" under the categories Border, HIV, and Health Services. This determined the ranking of articles. When a column had a "Yes" for more than one category (i.e., border, HIV or health services), a rank of first – fourth tier was added to the rank column. Articles which have nothing to do with any of these categories were marked as excluded or not meeting inclusion criteria.

The constructs selected to rank articles were based on the research question, "*What are the organizational barriers to coordinated HIV prevention across jurisdictional borders*." The term "borders" was selected because of the focus on jurisdictional border. Jurisdictional border was one of the more difficult constructs to abstract from articles. The MeSH database suggested "immigration," "emigration," and "migrant" as terms that would query articles related to "border." Immigration, emigration, and migrant are about an individual's movement from one place to another, often across a border; however, this does not often cover an organization's coordination and collaboration across a jurisdictional border to serve the migrating population.

Deciding whether or not to mark an article as including discussion of HIV was usually clear. However, there were few articles which did not discuss coordination of care for HIV, but discussed infections with similar risk factors and treatment, such as Tuberculosis, Hepatitis C, and other STDs. Since the purposes of the ranking were to 1) further define and bring context to the HSUM constructs and 2) identify organizational

barriers to coordinated HIV prevention across jurisdictional borders, articles were not included unless they specifically mentioned HIV.

The research question does not specifically include the term “health services,” however, after the process of searching for key terms in PubMed and using those key terms to identify articles led to the realization that the term “health services” was more appropriate in identifying articles about organizations which provide HIV prevention services, and therefore may need to coordinate those services. Consequently, though the purpose of the research is to identify “organizational barriers” it is equivalent to identifying “health service organization barriers.” The implication of this change in language is that in reviewing articles to rank them, articles which involved discussion of health services were ranked – not simply articles discussing “organizations.”

During the analysis of titles, a column labeled “Country” was also added to identify the geographical region of the research study to inform the possible generalizability of the results. Some articles discussed borders including the United States, while others discussed borders between countries on other continents. Differences in healthcare systems in other regions could make articles more or less relevant to this study; however, articles from all countries were included in this review. This also proved helpful in identifying gaps in the literature, for example, having few studies of borders within the U.S. and more studies of borders outside the U.S. After a first review of titles, abstracts were reviewed to determine the rank of articles which could not be ranked by title alone. Occasionally, the full-manuscript was reviewed to determine whether the article focused on borders, HIV, and/or health services.

Higher ranked articles were reviewed first, and were considered more important in defining terms in the code dictionary. First tier articles were reviewed first for barriers to coordinated HIV prevention across state jurisdictional borders. Articles were also reviewed for whether they relate to any of the following categories: *organizational barrier, border-related barrier, coordinated HIV prevention, need to address jurisdictional border, borders as a barrier to health, borders as a barrier to HIV prevention, trust, border-based discrimination and disparity, cultural differences, economic differences, agency/organization, HIV/AIDS prevention, state/jurisdictional border, coordination/cooperation, collaboration on specific issues, barriers/challenges, and metropolitan area/urban area*. All first tier articles were downloaded for further review, and information from the articles was entered into the literature matrix. Information related to the research question, "*what are the organizational barriers to coordinated HIV prevention across jurisdictional borders*?" and information which helps to define borders and HSUM constructs was abstracted from the articles and entered into the literature matrix.

.

After all the A-ranked articles were reviewed and abstracted into the matrix, the matrix information was reviewed for *organizational barriers to coordinated HIV prevention across jurisdictional borders*, to determine if any new constructs should be added to the HSUM model. During that process, constructs identified in the literature which validated the existing definition of HSUM, or contributed to construct definitions were noted and added to the document, *Definition of HSUM terms based on results of MMLR process* (Appendix G). Abstracted information under each keyword in MMLR

was read, summarized, and re-stated as a definition for the term. Next, a new table was created to compare the pre-existing HSUM constructs and construct definitions with the new constructs identified through the MMLR process (Appendix H). This new table, *Comparison of HSUM definition before and after MMLR process* (Appendix H) used definitions created by summarizing what was learned from the MMLR and comparing those definitions to the original definition of HSUM by the UN (United Nations Economic and Social Council, Committee on Economic, Social, and Cultural Rights, 2000), Sophia Gruskin and colleagues (Gruskin, Bogecho, & Ferguson, 2010) and Zuniga and colleagues (Zuniga, et al., 2006). Finally, the construct definitions from before and after the MMLR process were summarized into sub-constructs of each of the four constructs and compared in the results table (table 5.4.2).

5.4 Results

A total of 260 articles were abstracted into the Literature Matrix, and organized around the Health Service Utilization (HSU) framework: Accessibility, Acceptability, Accountability, and Availability. The articles were then ranked based on their discussion of borders, HIV and health services.

5.4.1 Results of Document Rank and Review

Of 260 articles reviewed, 212 articles (82%) included some discussion of Health Services, and of those, 43 (20%) discussed a jurisdictional border. There were 14 articles (5%) which related in some way to organizational barriers, jurisdictional border, and health services. Of 260 articles reviewed, 96 (37%) included discussion of “borders,” as either jurisdictional borders, migrant populations, or populations residing in borderlands. However, only 45 articles (17%) discussed a state or jurisdictional border. Only 2

articles (<1%), discussed borders and HIV (Table 5.4.1). Of 260 articles reviewed, 45 articles (17%) included some discussion of HIV and 23 (9%) discussed HIV and health services. Table 5.4.1 below shows the results of the ranking process. There were 14 first tier articles, 64 second tier articles, 23 third tier articles, and 2 fourth tier articles.

Table 5.4.1 Number of Articles Identified by Rank

	First tier (borders, HIV, & health services)	Second tier (borders & health services)	Third tier (HIV & health services)	Fourth tier (borders & HIV)	Total ranked
Acceptability	**0**	8	0	1	9
Accessibility	**4**	43	2	0	49
Accountability	**5**	3	2	0	10
Availability	**5**	10	19	1	35
Total	**14**	64	23	2	103

The full-text versions of first tier articles were reviewed to refine and expand upon the definitions of Health Service Utilization Model, Accessibility, Accountability, and Availability. Since there were no first tier articles for Acceptability, the eight second tier articles were reviewed for the definition of Acceptability. While the second tier articles contained content which validated the original definition of HSUM constructs, unlike the other constructs were first tier articles were available, the second tier articles did not contribute any new sub-constructs to the definition of HSUM constructs.

5.4.2 MMLR to validate and operationalize HSUM for organizational barriers to HIV prevention

Due to the lack of a clear theoretical framework for thoroughly understanding and articulating organizational challenges to coordination in HIV prevention services in metropolitan areas that cross State jurisdictional borders, the Matrix Method of Literature Review was implemented to build support for a new model. The terms defined and

imported became the HSUM constructs: Accessibility, Availability, Accountability, and Acceptability. The MMLR process determined how the constructs of the model could be operationalized for organizational barriers to coordinated HIV prevention, and also provided some validity to the model when the literature supported the pre-existing definition of the constructs or used the constructs together in a study.

Detailed information on what was learned about the definitions of the HSUM terms through abstraction of first tier articles is provided in a table in Appendix G, "*Definition of HSUM terms based on results of MMLR process*." For each article, the table provides a summary of the article, a quote from the article which speaks to the HSUM term, and an interpretation of how the article adds to the definition of the HSUM term (i.e., HSUM construct definition). After this process, the HSUM construct definitions were combined for each article and incorporated into a single definition (Appendix G). This table was then simplified by summarizing definitions as sub-constructs of each of the four HSUM constructs (Table 5.4.2). These sub-constructs were compared with the pre-MMLR definitions of HSUM constructs and categorized as either validating the HSUM definition, operationalizing the HSUM constructs for the study research question, or adding new sub-constructs to the original HSUM construct definition.

Table 5.4.2 HSUM Definition before and after MMLR process

HSUM construct	Pre-MMLR	Post-MMLR	Differences
ACCESSIBILITY	• Non-discrimination • Physical accessibility • Client transportation • Service convenience • Economic accessibility • Affordability • Information accessibility • Literacy level of materials provided by providers • Special attention to vulnerable populations	• HIV-related stigma • Transportation • Clinic location • Clinic hours • Availability of childcare • Health insurance access • Awareness of existing services and eligibility • Allocations of funding • Patient-provider relationship • Cultural competence of providers • Technical competence of providers • Differences in health attitudes and beliefs	<u>Sub-constructs operationalized for borders and HIV with MMLR</u> - Non-discrimination (pre-MMLR) was further operationalized as "HIV-related stigma" - Physical accessibility was operationalized as transportation and clinic location in both pre and post MMLR codebooks - Service Convenience (pre-MMLR) was further operationalized as clinic location, clinic hours, and availability of childcare - Economic accessibility/ Affordability was further operationalized as health insurance access - Information accessibility/ Literacy level was further operationalized as awareness of existing services and service eligibility <u>Sub-constructs added based on MMLR results</u> - Allocations of funding - Patient-provider relationship - Cultural competence of providers - Technical competence of providers - Differences in health attitudes and beliefs <u>Sub-constructs only in pre-MMLR</u>: - Special attention to vulnerable populations
ACCEPTABILITY	• Services are respectful of medical ethics • Services are culturally appropriate • Services are congruent with client cultural	• Medical ethics • Perception of control over health and medical decisions • Confidentiality of health and medical information	• <u>Sub-constructs operationalized for borders and HIV with MMLR</u> - Patient attitudes towards health services (Lee JH, Goldstein MS, Brown ER, Ballard-Barbash R, 2010) more clearly summarizes several sub-constructs of acceptability, including: o Services consider social expectations

	expectations • Services respect patient confidentiality • Services improve patient health status • Services are sensitive to sex and life-cycle requirements • Services consider social expectations • Services consider language needs • Services address client comfort • Services address potential stigmas	• Cultural differences between patient and provider • Impact of disease stigma • Patient attitudes towards health services	o Services address client comfort o Services consider language needs o perception of control over health and medical decisions - Services are congruent with client cultural expectations was further operationalized as "Cultural differences between patient and provider" as this was discussed as important for vulnerable populations (Yennurajalingam S, Parsons HA, Duarte ER, et al., 2013; Sullivan LV, Hicks P, Salazar G, Robinson CK, 2010) <u>Sub-constructs validated through MMLR</u> - Services are respectful of medical ethics (Sullivan LV, Hicks P, Salazar G, Robinson CK, 2010) - Services respect patient confidentiality (Sullivan LV, Hicks P, Salazar G, Robinson CK, 2010) - Services address potential stigmas and impact of disease stigma (Bridges AJ, Andrews AR, Deen TL, 2012) <u>Sub-constructs only in pre-MMLR</u> - Services are culturally appropriate and are sensitive to sex and lifestyle requirements (Yennurajalingam S, Parsons HA, Duarte ER, et al., 2013; Sullivan LV, Hicks P, Salazar G, Robinson CK, 2010)
ACCOUNTABILITY	• Services are scientifically and medically appropriate and of good quality • Medical personnel are skilled • Treatments are effective and not expired	• Mechanisms to monitor quality of care. • Mechanisms to protect privacy of health and medical information • Mechanisms for consumers to participate in service decision-making • Mechanisms for patients	<u>Sub-constructs added based on MMLR results</u> - Mechanisms to protect privacy of health and medical information - Government agreement on policies affecting HIV epidemics and vulnerable populations <u>Sub-constructs operationalized through MMLR</u> - Services are scientifically and medically appropriate and of good quality (Mechanisms to monitor quality of care) - Medical personnel are skilled (Mechanisms to monitor quality of care)

	• Healthcare equipment is safe and sanitary • Mechanisms exist for healthcare consumers to participate in decision-making • Mechanisms exist for healthcare consumers to provide feedback on healthcare services • Mechanisms at local, national and/or international levels monitor compliance and support governments in fulfilling obligations to populations. • Health service system is responsive to client and community needs and/or concerns	to provide feedback on services • Government agreement on policies affecting HIV epidemics and vulnerable populations.	- Treatments are effective and not expired (Mechanisms to monitor quality of care) - Healthcare equipment is safe and sanitary (Mechanisms to monitor quality of care) <u>Sub-constructs validated through MMLR</u> - Mechanisms exist for healthcare consumers to participate in decision-making - Mechanisms for patients to provide feedback on services <u>Sub-constructs only in pre-MMLR</u> - Mechanisms at local, national and/or international levels monitor compliance and support governments in fulfilling obligations to populations. - Health service system is responsive to client and community needs and/or concerns
AVAILABILITY	• Healthcare facilities exist in sufficient quantities, relative to the population need in the geographic area • Existing healthcare facilities are sanitary • Trained medical professionals are available in sufficient	• Number of MSM-friendly providers • Availability of reliable, affordable diagnostic tests • Organization characteristics such as staff turnover and shortages • Health care worker migration	<u>Sub-constructs operationalized for borders and HIV with MMLR</u> - "Trained medical professionals are available in sufficient quantity" and - "Healthcare professionals receive competitive salaries" was further explained as "Health care worker migration" - "Healthcare facilities exist in sufficient quantities, relative to the population need in the geographic area" was contextualized as "Number of MSM-friendly providers" and "Availability of reliable, affordable diagnostic tests" <u>Sub-constructs added based on MMLR results</u>

	quantity • Healthcare professionals receive competitive salaries • Essential pharmaceutical treatments are available to fulfill the needs of the population	• Data systems for communication about available services and resources • Data systems for oversight of health care workforce • Number of clinics which respect patient privacy concerns • Power differentials • Social connectedness • Human capital	- Organization characteristics such as staff turnover and shortages - Data systems for communication about available services and resources - Data systems for oversight of health care workforce - Number of clinics which respect patient privacy concerns - Power differentials - Social connectedness - Human capital <u>Sub-constructs only in pre-MMLR</u> - Essential pharmaceutical treatments are available to fulfill the needs of the population - Existing healthcare facilities are sanitary

Accessibility. For Accessibility, both the U.N. General Comment definition and the MMLR articles describe Accessibility as including economic accessibility and affordability of services. Physical Accessibility is discussed in both the MMLR and the UN definition of HSUM as clinic location, hours of operation, and ability to get to facilities safely. However, the MMLR added to that definition, emphasizing that availability of childcare could impact accessibility for PLWH (Conviser R., 2007). Information accessibility was identified as part of the definition of accessibility in both MMLR and the UN definition; however the UN definition focused on this being a right of individuals to receive health information confidentially and the MMLR found information accessibility to be awareness of services and service eligibility (Servin AE, Muñoz FA, Strathdee SA, Kozo J, Zúñiga ML., 2012). The right of individuals to receive health information confidentiality was a prominent theme in articles identified under HSUM constructs acceptability and accountability. Stigma and non-discrimination were described in both the pre-MMLR and MMLR definitions of accessibility; however, in the context of HIV presented through the MMLR, patient-provider relationship was specifically identified as an important component of non-discrimination (Servin AE, Muñoz FA, Strathdee SA, Kozo J, Zúñiga ML., 2012).

There were five sub-constructs of accessibility which only emerged through the MMLR process and were not present in the previous definition. These include allocation of funds, patient-provider relationship, cultural competence of providers, technical competence of providers, and differences in health attitudes and beliefs.

There was one sub-construct of accessibility in the pre-MMLR definition that was not identified in the systematic literature review. “Special attention to vulnerable

populations," was added to the definition of accessibility when Sophia Gruskin and colleagues pointed out that non-discrimination, physical accessibility, economic accessibility, and information accessibility affect vulnerable populations more than others (Gruskin, Bogecho, & Ferguson, 2010). For example, Gruskin and colleagues suggested that interviews with hard-to-reach populations should be a part of an organizations self-assessments (Gruskin, Bogecho, & Ferguson, 2010) to ensure human rights related to health are not violated.

Acceptability. The definition of Acceptability prior to this research process consisted of 10 sub-constructs (see table 5.4.2). After the systematic literature review, 6 sub-constructs were added, which further define Acceptability in the context of coordinated HIV prevention across jurisdictional borders. In both the MMLR and pre-MMLR definitions of Acceptability, there was discussion of medical ethics, confidentiality, stigma, and client cultural expectations. However, in the MMLR, acceptability also included discussion of patient attitude towards health and medical services (Lee JH, Goldstein MS, Brown ER, Ballard-Barbash R, 2010). The MMLR articles further explained how cultural expectations affect acceptability of healthcare. This barrier to healthcare was defined as "perception of control over health and medical decisions," and this was found to be of particular importance for vulnerable populations (Yennurajalingam S, Parsons HA, Duarte ER, et al., 2013; Sullivan LV, Hicks P, Salazar G, Robinson CK, 2010). There was also discussion of how border crossing can impact patient perception of service acceptability. For example, a patient may be accustomed to a certain level of service or patient-provider rapport in one jurisdiction, and this may be different across a border were culture may also differ.

Availability. Availability was defined by five sub-constructs prior to the MMLR process: sufficient healthcare facilities to meet need in geographic area, sanitation of existing health care facilities, supply of trained medical professionals, competitive salary of healthcare professionals, and existence of essential pharmaceutical treatments (table 5.4.2). Some of these sub-constructs were further explained by the MMLR process. For example, many of the availability studies addressed "brain drain" which occurs when healthcare professionals migrate from a region (usually a poorer country) to work in a region with more opportunity for competitive salary. The articles identified in MMLR also contextualized availability of providers as "number of MSM-friendly providers," reflecting the concern that when few providers who exist, there are likely going to be fewer providers who can respond to varying cultural and personal needs of patients; thus affecting acceptability of care.

Seven new sub-constructs were added to the definition of availability as a result of the MMLR process. Organizational characteristics, such as staff turnover, were discussed in several articles as impacting the availability of healthcare. Data systems were mentioned in several articles describing availability of health services, borders, and HIV. Some articles also discussed the use of data systems to disseminate information to the public about service availability.

Accountability. The literature about Accountability identified prior to MMLR was extensive, yet inconsistent. The fourth component of the HSUM model, in some studies accountability was replaced by "quality" (U.N. General Comment No.14). In other studies, there was much variation in how accountability was defined. Eight unique sub-constructs of accountability were identified prior to the MMLR process. The MMLR

process added five sub-constructs; however, three of which simply operationalized the previous sub-constructs for the study of borders and HIV. The two unique sub-constructs added to the definition of accountability are "*mechanisms to protect privacy of health and medical information*" and "*government agreement on policies affecting HIV epidemics and vulnerable populations*."

5.5 Discussion and Implications

This study found that the constructs of HSUM (i.e., accessibility, availability, accountability, and acceptability) encapsulated organization-level barriers to cross-jurisdictional HIV prevention. The articles identified through the MMLR process revealed the HSUM appears to be a comprehensive and valid way of conceptualizing cross-jurisdictional borders as barriers to coordinated HIV prevention. The MMLR process provided a standardized method to operationalize the constructs of HSUM for organizational barriers to cross-jurisdictional collaboration for HIV prevention and proved useful in building on existing knowledge of HSUM as a theory. In addition, the process of examining HSUM through the MMLR identified gaps in the literature, where HSUM constructs have not been thoroughly explored for addressing HIV prevention challenges or border-related barriers to care. Finally, these new, more clearly defined constructs could provide a useful tool for deductive analysis of qualitative data on HIV, borders, and health services, using HSUM as a framework.

5.5.1 HSUM as a comprehensive and valid way of conceptualizing cross-jurisdictional borders as barriers to coordinated HIV prevention

Both the World Health Organization and the United Nations have acknowledged the HSU Model; however, it was not clearly operationalized; nor applied consistently using the same constructs and the same definitions for those constructs. Prior to this study, the only study to apply the HSUM constructs in the context of HIV prevention and jurisdictional border only used three of the four constructs and did not define the constructs the same way as prior studies or reports (Zuniga et al., 2010). The MMLR was utilized in this study to examine the validity of the HSUM and to explore how HSUM was operationalized in studies about organizational barriers to provision of health services, specifically HIV prevention, across jurisdictional borders. Therefore, before the HSUM could be used as a framework for study of the research question, it was important to examine how HSUM constructs were defined and operationalized in the literature. The process of thoroughly examining the individual constructs in the literature provided thorough, reliable, contextualized definitions of terms which were previously not defined clearly or consistently.

5.5.2 Building on existing knowledge of HSUM as a theory and identification of gaps in the literature

The process of developing the MMLR was important in obtaining a clear, thorough definition of the constructs of the HSUM. Articles identified through the process were reviewed for how they discussed HSUM constructs. Those definitions were combined and became sub-constructs defining each construct in the HSUM. The MMLR process also allowed insight into contexts for which constructs of the model have been

studied, and showed gaps where constructs have not been studied. In all HSUM constructs, elements of the original construct definition were also identified through the MMLR process (See Table 5.4.2), however, the degree to which constructs were further defined, operationalized, or added to the definition varied. The following will discuss what was learned about each construct from HSUM and the implications of this new information.

Accessibility. Physical Accessibility is discussed in both the MMLR and the UN definition of HSUM as clinic location, hours of operation, and ability to get to facilities safely. However, the MMLR added to that definition, emphasizing that availability of childcare could impact accessibility for PLWH (Conviser R., 2007). The UN definition of accessibility also focused on the right of individuals to receive health information confidentially. However, in articles identified through the MMLR process the right of individuals to receive health information confidentiality was a prominent theme under the acceptability and accountability constructs. Through the MMLR process, information accessibility was operationalized as awareness of services and service eligibility (Servin AE, Muñoz FA, Strathdee SA, Kozo J, Zúñiga ML., 2012). Awareness of services and service eligibility were also identified as barriers to cross-jurisdictional HIV prevention in a previous qualitative study of HIV prevention stakeholders on each side of a jurisdictional border (Aldoory, Bellows, Boekeloo, Randolph, In Press 2015).

Characteristics of healthcare providers, including cultural and technical competence, health attitudes and beliefs, and ability to relate to a patient only emerged through the MMLR process as descriptors of accessibility, and were not present in the previous definition. Competence of providers was seen as influencing patient's access to

care, as were individual beliefs about health and self-care (Conviser R., 2007; Keesee MS, Natale AP, Curiel HF., 2012). Allocation of funding also emerged through MMLR and was not present in the pre-MMLR definition. For example, allocation of funding specific to the border was described as health insurance which can be used on both sides of a jurisdictional border (Servin AE, Muñoz FA, Strathdee SA, Kozo J, Zúñiga ML., 2012).

Acceptability. The MMLR process identified only 31 articles which related to acceptability. This provides evidence that the construct acceptability should be explored more, especially in the context of HIV, health services, and borders. Only one of the 31 articles included some discussion of HIV and none of the articles included discussion of HIV, borders, and health services. Therefore, there were no A-ranked articles for the HSUM construct, acceptability (table 5.4.1). This indicates a lack of research interest in acceptability of care among people living with HIV. Since acceptability of care is a barrier to seeking services and treatment consistency, it is especially important that care acceptability is explored for people living with chronic medical conditions like HIV.

Though there were no A-ranked articles, B-ranked articles were reviewed for sub-constructs which could validate, further define, or add to the definition of the HSUM construct, acceptability. Though the articles confirmed existing definitions of acceptability, and two sub-constructs were operationalized further, no new sub-constructs were identified which could add to the definition of acceptability. Though initially disappointing, this finding is important because it provides evidence that the methodology used in this study was appropriate for building upon HSUM as a theory. For each other HSUM construct, A-ranked articles produced sub-constructs which built

upon HSUM construct definitions. This was not the case for acceptability, likely because no A-ranked articles were available.

Availability. The MMLR process provide much more information about the importance of availability as a necessary component of health service utilization and also shed light on how the construct availability is necessary to address coordination of HIV prevention across jurisdictional borders. Seven new sub-constructs were added to the definition of availability as a result of the MMLR process. Organizational characteristics, such as staff turnover, were discussed in several articles as impacting the availability of healthcare. As staff remain at an organization, they obtain tacit knowledge, such as organizational knowledge and knowledge of the community they serve, which is not easily obtained through training of new staff. When turnover is high, an organization is left in a position of frequently relying on inexperienced staff, less likely to provide the best quality service possible. Minimizing staff turnover could be a priority for capacity building assistance programs working with HIV prevention organizations.

Data systems were mentioned in several articles describing availability of health services, borders, and HIV. As public health and medicine move away from paper-based systems and towards the use of EHRs and other data surveillance systems, the ability for these data systems to communicate with each other across jurisdictional borders becomes increasingly important. Some articles also discussed the use of data systems to disseminate information to the public about service availability. In this information age, most people seek information on the internet and it is important that information about HIV services are available online so people know how to access services which exist in their jurisdiction and neighboring jurisdictions.

Accountability. The literature about Accountability identified prior to MMLR was extensive, yet inconsistent. The MMLR process added five sub-constructs; however, three of which simply operationalized the previous sub-constructs for the study of borders and HIV. The two unique sub-constructs added to the definition of accountability are *mechanisms to protect privacy of health and medical information* and "*government agreement on policies affecting HIV epidemics and vulnerable populations*. These new constructs are important in addressing coordinated HIV prevention across jurisdictional borders. Jurisdictions have policies (including privacy policies) in place which govern their response to HIV and influence the abilities of individuals at living with- or at risk for HIV, as well as those who plan and implement prevention and care programs for those individuals. When bordering governments have conflicting policies affecting HIV epidemics and vulnerable individuals, coordinated prevention efforts are severely hindered.

5.5.3 HSUM as a framework for deductive analysis of qualitative data on HIV, borders, and health services.

This study demonstrates a new method for defining constructs to be used for coding qualitative research. In qualitative research, it is often important to develop a coding scheme, or a code dictionary so it is clear how segments of text should be coded. Often, the definitions for codes come from the qualitative researchers experience with the research topic, experience participating in the focus groups, or prior knowledge of a topic. Incorporation of the MMLR process allows the research to be more thorough and more objective in defining terms in a codebook. Using MMLR, the researcher can identify a clear definition that is not open to multiple opinions, biases or interpretations,

which often make the coding process difficult and lengthy. Instead, the code definitions become based on a body of literature, therefore, reducing potential bias of researchers own perceived definition of terms, and developing an evidence-base for qualitative analysis of the data. A deductive qualitative analysis relies on a well-defined coding scheme to assure that all relevant segments of text are included in the coding process, and that all relevant segments are coded consistently.

If the qualitative data analysis supported the HSUM, and relationships between the HSUM constructs could be hypothesized based on the qualitative findings, resulting in a more descriptive model of organizational barriers to coordinated HIV prevention across a jurisdictional border within each of the four health service utilization constructs. If none of the data supports the proposed health service utilization model, a new model for explaining organizational barriers to coordinated HIV prevention across jurisdictional borders could be created based on themes that emerge from the data and the grouping of themes into constructs, and relating these constructs to each other.

5.5.4 Study Limitations

The MMLR process added necessary rigor to an exploration of the HSUM model constructs in relation to barriers to coordinated HIV prevention across jurisdictional borders. There were, however, several limitations to this study that should be considered.

PubMed. Only the PubMed database was used to search for literature in this systematic review. The goal was to understand how organizational barriers to coordinated HIV prevention across jurisdictional borders is addressed in current public health literature. PubMed is a database which indexes articles of relevance to public health and

medicine. Prior to MMLR, other databases were queried for organizational barriers to coordinated HIV prevention across borders and the only difference is that some articles from communications literature, feminist literature, and business management fields were identified. These articles were often of little relevance to the study of the impact of borders on HIV prevention. Therefore, though other databases could have been selected for this study, PubMed was deemed most appropriate to achieve the study aims. Future research may consider comparing results derived from PubMed with results derived through other search databases, like Google Scholar or Medline.

PubMed indexing related to Organizational barriers to cross-jurisdictional collaboration. Through the MeSH terms search in the beginning of the MMLR process, much was learned about the terms PubMed uses to index this topic. There was no MeSH term for borders; however, there were terms for migrants and transients, or people who may cross borders. While this was helpful to have some index terms for learning about articles which discuss borders, this tends to pull up articles about the individual as the unit of analysis. This limits the number of articles which may surface that discuss the organization as the unit of analysis for understanding border-related barriers to health service utilization.

5.5.5 Conclusions

The HSUM provides a framework for identifying potential barriers to organizational coordination across jurisdictional borders for HIV prevention. Identifying these challenges/barriers can be helpful in developing solutions to coordination in HIV prevention service in metropolitan areas that cross jurisdictional borders. Future studies

should analyze the gaps in the literature related to HIV, borders, and health services, which were identified in this study.

Chapter 6 Summary

6.1 Summary of aims achieved through manuscript 1

The aim of the manuscript, "*HIV Prevention Organizations' expertise in serving HIV-vulnerable populations: Investigating community concerns*" was to examine stakeholder perceptions of HIV prevention challenges and the extent to which there are disconnects between the services available to vulnerable populations. This study found that HPO expertise varied with different sub-populations at-risk for HIV. A majority of HPOs serve and perceive *High Expertise* with African American or Black, Hispanic/Latino, and Youth. Though these populations tend to be more vulnerable to issues of healthcare access than majority populations, in terms of availability of care providers in this case study regions, they fared better than other populations at risk for HIV. Many HPOs lacked *High Expertise* with 12 of the 15 populations especially vulnerable to HIV and social marginalization. Specifically, few HPOs self-reported high expertise with sex workers, IV drug users, and transgendered populations. The trend identified in the data showed that there is less HPO expertise with populations served infrequently by HPOs. Organizations serving HIV vulnerable populations may benefit from capacity building to improve their expertise in the prevention and care of the most vulnerable populations. Alternatively, interdisciplinary service integration (e.g., the medical home concept) within and among health services for HIV may improve vulnerable persons' access to care from providers sensitive to their needs.

6.2 Summary of aims achieved through manuscript 2

The aim of the manuscript, "*Stronger United than Detached: A Descriptive Study of Cross-Jurisdiction Collaboration among HIV Prevention Organizations*" was to describe collaboration between HIV Prevention Organizations (HPOs) and correlates of collaboration across a jurisdictional border. Half or more of participating organizations agreed that benefits for cross-jurisdictional collaboration include *service improvement, potential for more funding,* and *efficient use of funds*. Nevertheless, half or more also perceived lack of resources and staff as barriers. Low perceived resources and staff may be a deterrent to urban/suburban partnerships for grant-seeking. Barriers to collaboration were statistically correlated with cross-jurisdiction grant-efficacy indicating that addressing some barriers to collaboration may be important in encouraging cross-jurisdiction grant partnerships. Although HPOs perceive multiple benefits to cross-jurisdictional collaboration, they also perceive barriers which may impede cross-jurisdictional efforts and hence further examination of the barriers to cross-jurisdictional collaboration is warranted to enhance the effectiveness of HIV prevention services.

6.3 Summary of aims achieved through manuscript 3

The aim of the manuscript, "*Exploring the utility of the Health Services Research Utilization Model to explain organizational barriers to coordinated HIV prevention across jurisdictional borders*" was to determine whether the MMLR further defines, operationalizes, and validates the Health Services Research Utilization Model as a comprehensive and useful model to examine and explain organizational barriers to coordinated HIV prevention across jurisdictional borders. The findings from this study indicated that the Health Service Utilization Model is an appropriate framework for

identifying barriers to organizational collaboration across State borders. This finding has the potential to aid metropolitan areas in addressing epidemics that cross State borders. Though HIV prevention was the topical focus of this study, the concepts identified to address collaboration may apply to other disease epidemics, such as Hepatitis C or syphilis, or influenza. Identifying these challenges/barriers can be helpful in coming up with solutions to lack of service coordination in metropolitan areas that cross State jurisdictional borders. Finally, this unique methodology provided a more rigorous approach to defining constructs which could be utilized in coding scheme development for analysis of qualitative data on this topic.

6.4 Limitations of case study methodology

The results of this study may be generalizable to HIV epidemics spanning international borders, as well as domestic borders. There are other areas in the U.S. experiencing an HIV epidemic as well as resource disparity across metropolitan jurisdictional borders. There are currently 53 recipients of Ryan White Care Act Part A funding to "Hard Hit Urban Areas." These regions often cross jurisdictional borders, requiring the need for collaboration and coordination between entities involved in HIV prevention efforts (Ryan White Target Center website https://careacttarget.org/grants/58). Some of these regions also cross state borders, such as the New York MSA (i.e., NY, NJ, and PA), the Chicago MSA (i.e., IL, IN, and WI), and the Philadelphia MSA (i.e., PA, NJ, DE, MD).

While challenges related to collaboration for HIV prevention are not unique to the case study area, there are some characteristics of the case study region which may make it unique. In the state of Maryland, the geographic location of the state health department is

in Baltimore City, which is experiencing an HIV epidemic and has its own unique challenges to HIV prevention. The case study region borders the District of Columbia, the city (district) with the largest HIV epidemic in the country. Because the case study region is between two major HIV epidemics, but is located outside of the jurisdiction border of these epicenters, responsibility for the case study region is often unclear between political leaders. The case study region is in the state of Maryland; however its population tends to migrate the porous border between Washington, D.C. and the state of Maryland. Still, transient and migratory populations are challenges to HIV prevention across the world (MacPherson, Douglas and Gushlak, 2011; Soskolne and Shtarkshall, 2002; Sangaramoorthy, 2008; Miller-Thayler, 2010)."

6.5 Conclusions and Recommendations for future study

This study provided a methodology for identifying barriers to organizations coordinating HIV prevention services across State borders. Identifying these challenges/barriers can be helpful in coming up with solutions to inefficiencies in HIV prevention service in metropolitan areas that cross State jurisdictional borders. Based on what was learned through all three manuscripts, there are several recommendations for addressing coordinated HIV prevention across jurisdictional borders:

Recommendation 1: Future studies should examine the relationship between vulnerable populations served by HPOs and the level of competency of the HPOs to serve such populations.

Recommendation 2: *HIV prevention organizations should consider strategies to increase their competence with vulnerable populations, including: a) reviewing data surveillance systems to ensure that care for vulnerable populations (e.g., sex workers, IV drug users, and transgendered individuals) can be tracked and monitored, b) working with providers to help them develop competence with vulnerable populations who they may see least frequently, c) collaborating with organizations that have competence with these vulnerable populations and developing joint provider training programs, and d) ensuring that appropriate follow-up and referral can be offered to patients with whom providers feel least competent.*

Recommendation 3: Studies of vulnerable populations should consider community-based participatory research as an approach to first 1) understand a community needs and assets through quantitative and qualitative data gathering, 4) look to the literature for similar community concerns and effective solutions, 3) with the advice of community leaders, identify and implement solutions to challenges identified by the community.

Recommendation 4: The survey measures produced for the manuscript, "Stronger United than Detached: A Descriptive Study of Cross-Jurisdiction Collaboration among HIV Prevention Organizations" should be evaluated for validity and reliability with a larger population of HPOs on both sides of a jurisdictional border. The measures are unique in that they were created through a community-based participatory research process, and they showed good internal consistency with this study population.

Recommendation 5: The benefits and barriers which prove to be most relevant to HPOs should be used to guide funding priorities which encourage HPOs to overcome some of the barriers identified. Also, as lack of consistent resources are often a challenge to collaborative efforts, long-term funding for HIV prevention projects should be an important goal.

Recommendation 6: The HSU framework warrants further study as a predictor of HIV prevention organization's likelihood of cross-jurisdictional coordination/collaboration across State borders, since evidence suggests HIV services may be delivered more efficiently, and in a manner more acceptable to the communities they serve when organizations collaborate.

Recommendation 7: A study using cluster analysis should be considered to further explore concepts related to stakeholder perceptions of cross-jurisdictional collaboration. Cluster analysis is an exploratory data analysis technique, which sorts data into clusters which share similar characteristics. Clusters based on variable means or based on distribution of data could allow examination of how groups of HPOs are similar or different. These clusters could then be compared to barrier variables to attempt to understand characteristics of organizations perceiving barriers to collaborating across the jurisdictional border and those who perceive fewer barriers.

Recommendation 8: The resulting HSUM definitions should be used to qualitatively analyze community stakeholder data on benefits and challenges to cross-jurisdictional

collaboration. This process would further validate HSUM as a model for understanding and addressing barriers to coordinated HIV prevention across jurisdictional borders.

Appendix A: IRB Approved Moderator Guide

Moderator's Guide

A = Foundations and Agencies interested in funding STD/HIV prevention
B = Government Agencies
C = Medical Clinical Personnel that deal with STD/HIV prevention
D = CBOs and Non-Profits working with STD/HIV prevention
E = MALE and FEMALE Community Residents
F = University students interested in STD/HIV prevention

***Introduction* (5 minutes)**
We would like to thank you in advance for your participation in this (FOCUS GROUP OR INTERVIEW). I will begin by asking everyone to turn off cellular phones, pagers, and any other audible device, as this focus group will be audio recorded. My name is (MODERATOR NAME), and I will be leading the discussion. This is (NAME), and s/he will be taking notes. This is (NAME), and s/he will be monitoring the discussion as well. We are with the University of Maryland Prevention Research Center. You have been gathered here today because you (*select for appropriate focus group)*

A. [are all **agencies** who have the ability to provide **funding** and resources for STD/HIV prevention programs that service individuals who live or work in Prince George's County, Maryland].
B. [work for a **government agency** that may provide STD/HIV prevention services to individuals who live or work in Prince George's County, Maryland.]
C. [are all **medical personnel**, who provide STD/HIV prevention services to individuals who live or work in Prince George's County, Maryland.]
D. [are all representatives of **organizations**, who provide STD/HIV prevention services to individuals who live or work in Prince George's County, Maryland]
E. [are all **residents** Prince George's County, and we are interested in your perceptions of STD/HIV prevention services in Prince George's County, Maryland]
F. [are all **students** at the University of Maryland who have expressed interest in STD/HIV prevention.]

We are interested in your perceptions of STD/HIV prevention in Prince George's County, Maryland. We would also like to get your feedback about an idea we have to create an online system to increase partnership and collaboration between funding agencies, government health departments, academics, CBOs and other organizations who do STD/HIV prevention work. The overall goal is to increase the effectiveness of STD/HIV prevention in Prince George's County neighborhoods with high STD/HIV incidence rates. In particular, we are focusing on neighborhoods within the National Capital Beltway.

This focus group will last approximately one and a half hours. It will be audio-taped, and note takers are present to document the discussion. The tape and notes will be used to make sure that we record all of your comments (in your own words) and to assist us in reviewing your remarks during the analysis of this focus group. You will not be identified in any way during the analysis, and the responses you provide will remain confidential. Your participation is completely voluntary. You may decide not to talk or take part in the discussion at any time. If you decide to leave, please keep all responses you heard here confidential.

[*FOCUS GROUP ONLY*: Please respect other individuals' opportunities to respond to each question. Allow one person to speak at a time without interruption.]

There are no right or wrong answers. **Your opinions, thoughts, and suggestions are extremely valuable to our research**. We encourage honest participation. Please feel free to respond to the question(s) to which you have a valuable response, [*FOCUS GROUP ONLY]* especially if you have a view or opinion different from others in the group. I would just like to ask that you speak one at a time and that everyone participate.

- [Does anyone/Do you] have any questions about this process before we begin?

Answer and take note of any questions before moving forward

I am going to begin the audio recording now.

Start tape now. For each of the following questions, ask participants to respond with yes or no. Do not proceed with recording until everyone has responded "yes."

- Has everyone here been informed about this research and had the opportunity to ask questions prior to this recording?
- Has everyone here signed a written consent form about this focus group, and consented to being audio recorded?
- Has everyone completed the brief, anonymous demographic questionnaire?

[FOCUS GROUPS ONLY] ***Warm-up***
To start, let's go around and have everyone introduce themselves with first names only or a chosen pseudonym. Also, please tell us where you are from.]

Open-ended Questions
[E, F ONLY
Prince George's County Maryland is the 2nd leading jurisdiction in Maryland, (behind Baltimore City), with persons infected with HIV/AIDS. The county also ranks 2nd behind Baltimore in cases of syphilis, gonorrhea, and chlamydia. STD rates in Prince George's County are 5-6 times greater than in Montgomery County. Between July 2004 and June 2005, 89% of new AIDS cases in Prince George's County occurred in African Americans. Prince George's County has identified sexual risks as priority health concerns for the county. **]**

This discussion will focus on preventing STD/HIV in Prince George's County. To clarify, "STD/HIV prevention," includes anything that would encourage safe sex practices, reduce infections or identify the need for treatment. Screening for STDs, HIV testing, condom distribution and educational information about STD/HIV are all examples of STD/HIV prevention. Clinical and medical treatment of infection is not included in this description. Organizations could provide this prevention through formal education, advertisements, public service announcements, screening opportunities, brochures, fliers, activities, entertainment events, health fairs, etc.

Do you have any questions about what I am referring to when I say, "STD/HIV prevention?

Address any questions before moving on to the next section

I. CHALLENGES AND OPPORTUNITIES FOR STD/HIV PREVENTION (10 MINUTES)

In the first part of this discussion, we would like you to discuss the challenges and opportunities for STD/HIV prevention in Prince George's County.

- What do you think are the challenges to STD/HIV prevention in Prince George's County, Maryland? *List challenges on white board or flip chart*
  - What makes it difficult for people to get HIV testing/screening, sexual risk and protection information, etc.?
- What could be done to overcome these challenges?
  - What do you think the community could do to make it easier for people to get STD/HIV prevention resources, information, or services?
  - What do you think it would take for people in your community to use existing STD/HIV programs?
- What opportunities exist in Prince George's County?
  - What is going on that could be built upon to improve STI/HIV prevention efforts? How about in other nearby communities?
  - Who is doing important work in the county that could be supported and expanded?

II. IDENTIFICATION OF STD/HIV PREVENTION ORGANIZATIONS (10 MINUTES)

For this next part of the [focus group/interview], I would like you to identify as many organizations providing STD/HIV prevention services as you can.

- Where do you think people usually get information about STD/HIV prevention?
- What organizations do you know of that provide STD/HIV prevention in Prince George's County? Remember, organizations can be small or large, local, national or international. They may be physically present in the local area or affect Prince George's County through the internet, mass media, etc.
- Which organizations do you know of that could provide STD/HIV prevention in Prince George's County if they had the motivation and resources?
- What organizations not located in Prince George's County do you know of that could provide STD/HIV prevention to Prince George's County residents?

Add questions for the following groups:

For A and B only:

- Which types of organizations would you make a high priority for supporting in this regard?

For C and D only:

- What organizations in neighboring jurisdictions are doing a good job in STD/HIV prevention? How could they help organizations in Prince George's County do a better job?

III. BENEFITS AND CHALLENGES OF COLLABORATION (15 minutes)
[only for groups A, B, C, D]

- How would organizations benefit from organizational collaborations?
- How would residents benefit?
- What are the challenges to organizational collaboration?
- What makes organizational collaboration difficult?
- What would make organizational collaboration easier?

IV. CONCEPTION OF AN ONLINE STD/HIV PREVENTION INFORMATION SYSTEM (15 MINUTES)

We have received funding to design an online system designed to increase collaboration between organizations and build capacity within organizations. The system would also be designed to catalog all STD/HIV prevention resources available to residents of Prince George's County, Maryland and provide an online space for community residents.

- What do you think about the idea of a Prevention Research Information System?
- Does anything like this already exist, that you know of?
- Which types of services would you want to be part of this system: STD/HIV prevention outreach, STD/HIV prevention education, STD/HIV testing and counseling sites, substance abuse and mental health, family planning, others?

If there was a website that cataloged STD/HIV prevention resources in Prince George's County, Maryland,

A. [How could funding agencies use this site?]
   a. How could it help funders to link with these organizations?
   b. As a funding agency, what kind of information would you want on this website?
   c. What would make it more likely that funders would utilize this website? What would make it less likely?
B. [How could government agencies use this site?]
   a. What kind of data collection would you want to see on this site?
   b. What would you want to know about STD/HIV prevention organizations?
C. [How could medical personnel use this site?]
   a. What information would you want your patients to have available to them?
   b. What kinds of resources would you want to provide to your patients through this site?
D. [How could CBOs use this site?]
   a. Would it be helpful to learn about other organizations working on STD/HIV prevention in your community?
   b. What kinds of information would you like to see on this site?
   c. What kinds of tools would be useful to you and your organization?
E. [How could community residents use this site?]
   a. What kind of information would be useful to you?
   b. What kind of web tools (i.e. blogs, message boards, events calendar, chat feature, etc.) would you like to see on the site?
F. [How could university students use this site?]
   a. What kind of information would you like to see on the site?
   b. How could you use this site to link with STD/HIV prevention organizations?

V. PROTOTYPE PRE-TEST (30 MINUTES)

We have identified potential prototypes of what this Prevention Research Information System might look like. As I show you these prototypes, I will ask you some questions. Please feel free to stop me or ask me to go back to a section we have already passed and share any thoughts, concerns or questions you may have. This is a lot of new

information so feel free to take time to process everything before you come up with questions.

Here are some examples of websites that provide certain functions which might be helpful in the development of PRIS. Please let us know your opinion of each of these as we go through them.
For each site, ask:

- What is your opinion about this web feature/tool?
- What (if anything) about this feature/tool would be beneficial in providing STD/HIV prevention resources?

[A-F] Web 2.0 which might be useful for organizations to showcase their work, or for community residents to express thoughts, concerns or ideas…
http://www.abovetheinfluence.com/speak/default.aspx?path=nav

[A-F] Map allows one to "Define your community" and find services in defined community. http://www.findyouthinfo.gov/default.aspx

[A-F] Resource of online tools for organizations www.innonet.org

[A-D Only] Nice home page – clear about goals and who site is for. Also, "join our community" link to a wiki. http://www.preventionworks.org/index.php

[E, F Only] Site for general public with section for "parents and teachers"
http://teens.drugabuse.gov/

[A, B, C, D Only]

- How would you feel about registering on a website so that the website could provide you with information on your specific interests and needs?
- How would you feel about having to log into a website each time you used it?

VI. Closure *(5 minutes)*

- Do you have any other ideas for improving STD/HIV prevention in Prince George's County?
- Do you have any final thoughts, concerns, questions or suggestions for the Prevention Research Information System (PRIS)?

Thank you for helping us out with this [focus group/interview] today! Your input has been very informative and will assist us in improving STD/HIV prevention efforts in your community. Please don't forget to take your incentive before you leave.

Appendix B: IRB Approved Survey Protocol

UNIVERSITY OF MARYLAND COLLEGE PARK
Institutional Review Board
Addendum Application

Protocol Number	10-0106
Protocol Title	UMD-PRC Pilot study: Developing a Prevention Research Information System
Risk Classification *(check one)*	☐ Greater than Minimal Risk ☑ Minimal Risk

Principal Investigator	Dr. Bradley O. Boekeloo	Email Address	boekeloo@umd.edu
Address for Approval Letter	University of Maryland School of Public Health Suite 2387 Valley Drive College Park, MD 20742	Telephone Number	301-405-8546

Student/Co-Investigators	Denise Bellows	Email Address	dbellows@umd.edu
Telephone Number	301-405-9114		

To ensure an accurate and streamlined review of your Addendum Application, please provide the following information:

1) State what is being proposed and where in the protocol and/or consent what was changed.

Since our last addendum was approved, May 12, 2011, we disseminated our survey to 90 organizations. Our response rate was less than 10%, which is unacceptable for this project. After receiving feedback, we learned that our population would likely be more receptive to this follow-up survey if several changes were made. In response, we have:

- Revised the survey to make questions more relevant to our cross-border collaboration focus and eliminated questions for which respondents might have to research their organization in order to answer.
- Changed the method of administration. Instead of having the option of online or paper survey, now the sample will be offered either a telephone interview or a face-to-face interview to complete the survey.
- Restricted this follow-up sample to only 30 of the original 90 organizations.
- Decided to provide a small gift card incentive for participation in this follow-up.
- Made the survey completely confidential such that answers will only be linked with an

organization code, not the organization name. Previously, a section of the survey was for public posting.

2) Provide the rationale/justification for the change.

- The revised survey will be more focused and easier to complete which may increase participation.
- The telephone interview or a face-to-face interview administration method will allow us to provide personal attention to respondents which may increase their participation.
- The 30 organizations are those that have been identified repeatedly as important for STD/HIV in our area. Hence, we will be able to focus our efforts on these pivotal organizations to increase participation.
- The small gift card incentive will encourage participation.
- The completely confidential survey will make participants feel more comfortable filling out sensitive information about their organization, and is likely to result in more honest and complete data.

3) State what impact the change has on risks to participants. Please state the number of currently enrolled participants and if the change in risk will require re-consent. If the changes will not require re-consent, please state why.

These changes are likely to have no impact on the risks to participants and may decrease risk in the form of survey burden. Nevertheless, all of the 30 participants in the follow-up sample will be newly consented. Of the 30 organizations in this follow-up sample, 10 have already partially or fully completed the initial survey and will be asked to consent to the follow-up interview that will verify their relevant data from the first survey administration and answer the new and revised questions.

4) State whether the change has an impact on the scientific integrity of the study, (i.e. decreases, increases, no impact).

The proposed change will likely increase our response rate and obtain more focused data in regard to our research questions and thus, increase the scientific integrity of the study.

5) List the documents included with the application that have been modified (consent forms, flyers, data collection forms, surveys). State what has been changed in each modified document.

1) Email Script for Scheduling Interviews(Appendix A): This is a new document

2) Phone Script for Scheduling Interviews (Appendix B): This is a new document

3) Consent For Phone Or Face-To-Face Structured Interview (Appendix C): The method of administering the survey has changed. Consent is now verbal, not online or on paper. The risks, benefits and confidentiality have also changed.

4) Structured Interview version of "Survey of Organizations in Metropolitan Washington" (Appendix D): This is the interview version of the approved paper survey, "Survey of Organizations in Metropolitan Washington." Parts of the survey that were difficult for respondents to answer were removed or re-worded to reduce respondent burden and increase clarity. A new section was added asking more questions about cross-border collaboration.

5) Maps Of Inner Beltway Prince George's County (Appendix E): Participants have informed us that the term "inner beltway" can be confusing and recommended providing maps to define this region during the structured interview.

APPENDIX A: Email Script for Scheduling Interviews

From: [dbellows@umd.edu]
To: [only individual's email address – hide others]

Subject: Request to Schedule an Interview

Date: [TBD]

Message:

Dear [Name],

In response to concerns about STD/HIV services identified in the Mosaica Profiles Project [1] and stakeholder focus groups and interviews conducted by the University of Maryland Prevention Research Center (UMD PRC) last summer, the UMD PRC is requesting an interview with you to measure opportunities and interest in collaboration to address these concerns. You are being invited to participate in this interview because your organization has been identified as a key STD/HIV service by stakeholders. Participation is completely voluntary. Please provide your availability on the attached interview schedule or call us at 301-405-2554 to make us aware of your interest and availability.

Thank you!

Sincerely,

Denise Bellows
Faculty Research Assistant
University of Maryland Prevention Research Center
School of Public Health
University of Maryland
301.405.2554
www.sph.umd.edu/umdprc

Bradley O. Boekeloo, PhD, ScM
Professor
Department of Public and Community Health
University of Maryland School of Public Health
College Park, Maryland 20742
301.405.8546
Email: boekeloo@umd.edu

Irwin Royster
Chair, Sexually Transmitted Infection Community Coalition (STICC)
202.489.1167
Email: irwin.royster@gmail.com

[1] "HIV prevention and community testing are insufficient" For more detail, see page 8 (12 of PDF) of The Profiles Project here:
http://www.mosaica.org/LinkClick.aspx?fileticket=zVLELzUzyRE%3d&tabid=2776&mid=5723

APPENDIX B: PHONE SCRIPT FOR SCHEDULING INTERVIEWS

Hello, may I please speak with _____?

Hi _____, my name is_____ and I am calling on behalf of the University of Maryland Prevention Research Center. We are focused on reducing health disparities in Prince George's County, and would like to set up a time to interview you about your STD/HIV prevention efforts. Participation is completely voluntary. Are you interested in participating?

[IF YES:]
When would be a convenient time for us to schedule an interview? The interview would take approximately one hour, and we can do it over the phone or in person at a location of your choice.

Thank you for your time and I look forward to speaking with you more on _____

Have a great day!

[IF NO:]
I am sorry to hear that. I would like to stress that this interview opportunity is only being offered to 15 organizations in Prince George's County and 15 organizations in Washington, D.C., and we have contacted you because we really value your opinion. Are you sure you are not available at all for a telephone or face-to-face interview?

[IF NO:]
I am sorry to hear that you are not interested in participating in this interview. The UMD-PRC is interested in your honest feedback so we may work towards improving our relationship with you and your organization in the future. Would you mind taking a minute to let me know why you chose not to participate?
[IF YES – RECORD REASON THEN CONTINUE TO 'END']
[IF NO]Thank you for your time. Don't hesitate to contact me if you change your mind. Have a great day!

[END] Thank you for your time! Have a great day!

APPENDIX C: CONSENT FOR PHONE OR FACE-TO-FACE STRUCTURED INTERVIEW

[Brackets are instructors to interviewer and should not be read aloud, unless italicized within brackets]Thank you for agreeing to set up this interview to discuss collaboration and STD/HIV prevention. I would like to start by reading you a brief description of the research project and giving you the opportunity to state your consent to being interviewed for the next hour. As I am reading, please feel free to ask questions or request that I clarify any section that is confusing. When I am finished, I will ask you to verbally consent to this interview by simply stating, "yes, I agree" or "no, I do not agree".

The name of the project you are participating in is: University of Maryland Prevention Research Center: Reducing Health Disparities in Maryland along the National Capital Border

[Project Administration:]

This research is being conducted by conducted by Bradley O Boekeloo, ScM, PhD, Director of the University of Maryland Prevention Research Center (UMD-PRC) at the University of Maryland School of Public Health at College Park. The UMD-PRC is funded by the Centers for Disease Control and Prevention. If you would like more information about the researcher and the UMD-PRC , please let me know and I will provide you with appropriate contact information.

[Purpose:] The purpose of this research is to better understand and document the challenges and opportunities for organizational partnerships, particularly those partnerships across the Washington, D.C. / Prince George's County border.

[Procedures:] This interview should take approximately one hour. The interview is divided into 9 sections. The sections are: 1) basic organization information, 2) boundaries of service, 3) types of prevention services provided, 4) areas of expertise, 5) working across borders, 6) collaboration across the Washington, D.C. / Prince George's County border, 7) involvement in partnerships, 8) organization staff and budget, and 9) contact information. This is a structured interview, meaning that questions are structured like a survey. While some questions are open-ended, many are closed-ended or multiple choice. After the interview, you will be sent an email with the researcher's contact information should you have any questions or concerns after the interview is over. As a token of our appreciation for your time, we will offer you a $20 Starbucks gift card or a University of Maryland mug.

[Potential Risks and Discomforts:] There are no direct risks to you or your organization.

[Potential Benefits:] This survey is part of a long-term plan by the UMD-PRC to develop new initiatives for improving community health. By providing information about your organization, the UMD-PRC will have the opportunity to inform others about challenges and opportunities for more integrated STD/HIV prevention across organizations. The UMD-PRC also hopes to develop partnerships which may lead to better services provided to the community. It is possible that this survey will have no direct benefits for your organization.

[Confidentiality:] The information you provide about your organization may be used by the UMD-PRC staff to develop appropriate partnership opportunities. For example, based on information you provide, the UMD-PRC may suggest to you that your organization could partner with another particular organization to respond to a funding opportunity. Beyond these purposes, the project staff will do everything they can to maximize the confidentiality of your data. No identifying information about your organization will be shared publically without your explicit permission. Your organization has already been assigned a code number for the purposes of this data collection. The data you provide in this interview will only linked to the research code, not your organization's name. The key linking your code and your organizations identity will be stored in a locked filing cabinet in the research lab. Only the research director, Dr. Brad Boekeloo, and research assistants under his direct supervision will have access to the key linking the research code and your organization's name. Results of this research will be reported about organizations as a group, not your individual organization.

[Right to Withdraw and Ask Questions:] Your organization's participation in this survey is completely voluntary. You may refuse to answer any questions and may choose to respond only to specific questions. Your organization may withdraw from the survey at any time without penalty.

Do you have any questions about what I just read to you? [If yes, answer question. If no, continue] If you find that you later have questions about this research study, you may contact the Project Director, Dr. Brad Boekeloo at 301-405-9114 or boekeloo@umd.edu.

Do you agree to participate in this interview? [If yes, end here and move on to interview]
[If No] I am sorry to hear that you are not interested in participating in this interview. If you change your mind at any point, please consider contacting me again. Thank you for your time. Have a great day.

APPENDIX D: STRUCTURED PHONE AND FACE-TO-FACE INTERVIEW

Survey of Prevention Organizations in Metropolitan Washington

[Brackets are instructions to interviewer and should not be read aloud, unless italicized within brackets]

The first part of this survey is going to ask detailed information about your organization and its collaborative activities and partnerships. When this research is complete, the University of Maryland Prevention Research Center may follow-up with your organization to ask questions about technical assistance and training opportunities that may interest your organization.

Section 1: Basic Organization Information
[Some of the data in this section was collected prior to the interview and would be located in the excel spreadsheet, "organization data"; therefore, tell participant, *"We have already obtained some basic information about your organization. Will you please confirm the following: (Organization name is … Organization website is… Organization address is…"* If data has not been collected prior, read the following:]

1.1 What is the name of your organization?

_____

1.2.1 Does your organization have a functioning website? Yes [continue] No [go to 1.3]

1.2.2 [*If yes,] what is the web address?

_____

1.3 Which of the following categories best describe your organization? Select all that apply.

(1) Academic/Educational/Training (2) Business/Corporation

(3) Community Center/Other Community-Based Organization

(4) Government/Military/Agencies

(5) Medical/Clinic/Hospital

(6) Non-profit/Charitable/Service-providing

(7) Professional Association/Society

(8) Religious/Faith-Based Organization

(9) Supra-organization (i.e. coalition, alliance, league, consortium, etc.)

(10) Other (Please specify)

1.4 Address of organization's central office:

Number, street, suite, P.O. Box: _____ _____

1.6 City: _____ 1.7 State: _____

1.8 County: _____ 1.9 Zip code: _____

Section 2: Boundaries of Service: In this section, we want to know how you would describe the population your organization serves.

2.1 Please define the **geographic borders that correspond to your organization's mission**.

_____

_____

2.2 I am going to read a few geographic descriptions. Please say, "yes" if this describes the population corresponding to your organization's mission, and "no" if it does not.

	LOCATION	YES	NO
2.2.1	Prince George's County	1	0
2.2.2	Washington, D.C.	1	0
2.2.3	Montgomery County	1	0
2.2.4	Inner beltway Prince George's County*	1	0
2.2.5	Wards 7 and 8	1	0

*Inner beltway Prince George's County is the region between the Washington, D.C. border and the National Capital Beltway. Here is a picture of the region:

[Display maps of inner beltway. If the interview is conducted via telephone, email inner beltway maps to participant.]

2.3 We are interested in learning about the specific types of populations your organization serves. Please respond, "Yes" if you know that your organization serves the population. Respond, "No" if your organization does not serve the population. If you are unaware whether the specific population is receiving services from your organization, please respond, "Don't know."

	POPULATION	YES	NO	Don't know
2.3.1	HIV/AIDS infected	1	0	9
2.3.2	Mentally Ill or disabled	1	0	9
2.3.3	IV Drug User	1	0	9
2.3.4	Sex Worker	1	0	9
2.3.5	Physically disabled	1	0	9
2.3.6	Clients with Substance Abuse Issues	1	0	9
2.3.7	Homeless	1	0	9
2.3.8	Sex Offender	1	0	9
2.3.9	Ex-Offender/Prisoner	1	0	9
2.3.10	STD infected	1	0	9
2.3.11	Youth	1	0	9
2.3.12	Men who have Sex with Men (MSM)	1	0	9
2.3.13	Transgender	1	0	9
2.3.14	Black or African American	1	0	9
2.3.15	Hispanic or Latino	1	0	9
2.3.16	Religious or faith-affiliated	1	0	9
2.3.17	Foreign-born or immigrant	1	0	9
2.3.18	LGBTQ	1	0	9

Section 3: Types of Prevention Services Provided

We have created four categories of Prevention Services that your organization may provide. For each prevention service type, I will ask you two questions: 1) the approximate number of individuals who utilize this service of your organization and 2) the approximate percent of those served who are Prince George's County residents. Please respond, 'not applicable' if your organization does not provide the service in question. The time frame for the number of individuals served by each activity is one year. I will also ask you whether the numbers you provide are estimates, or based on specific data collected by your organization. We would prefer

to have data, but we understand that estimates might be easier to obtain. Any data you can provide is appreciated.

	[Read the description for each category below]	Total number served in an average year	% Who are Prince George's County residents	Estimate or Data (check the appropriate box below)	
				Estimate	Data
3.1	**Education/Training/Counseling** (Group or individual counseling and/or education, outreach education, spiritual guidance, peer training, educational programs, etc.)	3.1.1	3.1.2	3.1.3	3.1.4
3.2	**Health and Medical Services** (Screening, preventive treatment, condom and/or contraception distribution, health system navigation, referrals, therapies, rehabilitation and other clinical services, etc.)	3.2.1	3.2.2	3.2.3	3.2.4
3.3	**Basic Social Services** (Housing, legal services, employment, food, clothing, transportation, etc.)	3.3.1	3.3.2	3.3.3	3.3.4
3.4	**Financial Support Services** (Grants, contracts, loans, etc.)	3.4.1	3.4.2	3.4.3	3.4.4

Section 4: Areas of Expertise

For each of the following services, I will ask you to rate your organization's in-house expertise. Please state whether your expertise is low, moderate, or high. If you are unsure about your organization's expertise, you may respond, "Don't know."

		Low Expertise	Moderate Expertise	High Expertise	Don't Know
4.1.1	**Education/Training/Counseling** (Group or individual counseling and/or education, outreach education, spiritual guidance, peer training, educational programs, etc.)	1	2	3	9
4.1.2	**Health and Medical Services** (Screening, preventive treatment, condom and/or contraception distribution, health	1	2	3	9

	system navigation, referrals, therapies, rehabilitation and other clinical services, etc.)				
4.1.3	**Basic Social Services** (Housing, legal services, employment, food, clothing, transportation, etc.)	1	2	3	9
4.1.4	**Financial Support Services** (Grants, contracts, loans, etc.)	1	2	3	9

This next set of questions is about in-house **expertise with specific populations**. For each item, please state whether your in-house expertise with this specific population is **low**, **moderate**, **high**, or that you **don't know**:

	Population	**Low Expertise**	**Moderate Expertise**	**High Expertise**	**Don't Know**
4.2.1	HIV/AIDS infected	1	2	3	9
4.2.2	Mentally Ill or disabled	1	2	3	9
4.2.3	IV Drug User	1	2	3	9
4.2.4	Sex Worker	1	2	3	9
4.2.5	Physically disabled	1	2	3	9
4.2.6	Clients with Substance Abuse Issues	1	2	3	9
4.2.7	Homeless	1	2	3	9
4.2.8	Sex Offender	1	2	3	9
4.2.9	Ex-Offender/Prisoner	1	2	3	9
4.2.10	STD infected	1	2	3	9
4.2.11	Youth	1	2	3	9
4.2.12	Men who have Sex with Men (MSM)	1	2	3	9
4.2.13	Transgender	1	2	3	9
4.2.14	Black or African American	1	2	3	9
4.2.15	Hispanic/Latino	1	2	3	9
4.2.16	Faith-based	1	2	3	9
4.2.17	Foreign-born or immigrant	1	2	3	9
4.2.18	LGBTQ	1	2	3	9

Section 5: Working Across Borders: This next section is asking about working across the Washington, D.C./Prince George's County border. Please remember that the data you provide are confidential. The data will only be connected directly to an ID number we create for your organization. The data will NOT be linked directly with your organization's name. Any reports written as a result of this data collection will display data in the aggregate.

5.1 Over the past 12 months, to what level did your organization **achieve its goals** related to HIV prevention activities in the following geographic areas? You may respond, "**we have no goals in this area**," "**no goals met**," "**goals met partially**," "**goals met completely**," or "**goals exceeded**."

		We have no goals in this area	No Goals Met	Goals Met Partially	Goals Met Completely	Goals Exceeded
5.1.1	Prince George's County	0	1	2	3	4
5.1.2	Washington, D.C.	0	1	2	3	4

5.2 For the next 12 months, how much does your organization **plan to expand its goals** related to HIV prevention activities in each of the following geographic areas? Please respond either, "**no expansion**," "**minor expansion**," or "**major expansion**."

		No Expansion	Minor Expansion	Major Expansion
5.2.1	Prince George's County	0	1	2
5.2.2	Washington, D.C.	0	1	2

5.3 Does your organization collaborate with any organizations on the other side of the Washington, D.C./Prince George's County border by providing services to residents or partnering on events and/or programs? **[**Once again, display the map of the inner beltway to show participants where the Washington, D.C. / Prince George's County border lies. If interview is conducted via telephone, email the maps to the participant. **]**

(1) Yes [Continue] (0) No [Go to question 5.5]

5.4 Please list the organization you partner with across the Washington, D.C. / Prince George's County border to provide services, events, and programs. Do not include partnerships in which services, events, or programs were planned but not executed.

_____ _____

_____ _____

_____ _____

_____ _____

5.5 Please estimate the percentage of your organizations overall effort (i.e. % of overall staff time) spent in each of the following geographic areas:

Once again, please be reminded that the data you provide will not be connected with your organization name, only by the organization ID number we created for the purposes of this research. Also, any reports written as a result of this data collection will report data in the aggregate.

	Region	Percent of Effort
5.5.1	Prince George's County, Maryland	
5.5.2	Washington, D.C.	
5.5.3	Montgomery	
5.5.4	NOVA	
5.5.5	**Total** [Does not have to total 100%; Organizations could work in other jurisdictions]	

Section 6: Collaboration Across the Washington, D.C. / Prince George's County Border

6.1 How much does each of the following affect your **willingness to partner** with another organization across the Washington, D.C./Prince George's County border on HIV/STD prevention efforts? For each item, please respond with either "**not at all**," "**very little**," "**somewhat**," or "**a lot**."

	[say, "*How much does _____ affect your willingness to collaborate?*" for each of the following]	Not at all	Very little	Somewhat	A lot
6.1.1	How much does **your organization's trust of the other organization** affect your willingness to collaborate **cross-border**?	0	1	2	3
6.1.2	How much does **your organization's expectation of gain from cross-border collaboration** affect your willingness to collaborate?	0	1	2	3
6.1.3	How much does **your organization's sense of power and control in cross-border collaboration** affect your willingness to collaborate?	0	1	2	3
6.1.4	How much does **your funders' stated support of cross-border collaboration** affect your willingness to collaborate?	0	1	2	3
6.1.5	How much does **your clients' support of cross-border collaboration** affect your willingness to	0	1	2	3

	[say, *"How much does _____ affect your willingness to collaborate?"* for each of the following]	**Not at all**	**Very little**	**Somewhat**	**A lot**
	collaborate?				
6.1.6	How much does **your organization's availability of resources for cross-border collaboration** affect your willingness to collaborate?	0	1	2	3
6.1.7	How much does **your organization's local health department stated support for cross-border collaboration** affect your willingness to collaborate?	0	1	2	3
6.1.8	How much does **type of population served in cross-border collaborative effort** affect your willingness to collaborate?	0	1	2	3
6.1.9	How much does **geographic area of population served in cross-border collaboration** affect your willingness to collaborate?	0	1	2	3
6.1.10	How much does **jurisdictional border** affect your willingness to collaborate **cross-border**?	0	1	2	3
6.1.11	How much does **expertise of the other organization** affect your willingness to collaborate? **[for example, whether organization expertise is similar or different]**	0	1	2	3
6.1.12	How much does **expectation about the size of the accessible population at risk** affect your willingness to collaborate?	0	1	2	3
6.1.13	How much does **perceived social prestige associated with the geographic area served** affect your willingness to collaborate?	0	1	2	3

6. 2 Barriers to Cross-border Collaboration: Please describe the extent to which each of the following is a barrier for your organization to work across the Washington, D.C. / Prince George's County border by responding "not at all, very little, somewhat, or a lot"

	BARRIERS	Not at all	Very little	Somewhat	A lot
6.2.1	How much does **competition for funding** affect your willingness to collaborate cross-border?	0	1	2	3
6.2.2	How much does **lack of time and energy** affect your willingness to collaborate cross-border?	0	1	2	3
6.2.3	How much does **similarity in mission and services** to other organizations affect your willingness to collaborate cross-border?	0	1	2	3
6.2.4	How much does **fear of loss of client trust** influence your willingness to collaborate with other organizations cross-border	0	1	2	3
6.2.5	How much do **negative prior experiences** with collaboration influence your willingness to collaborate with another organization cross border?	0	1	2	3
6.2.6	How much does **lack of follow-up** influence your willingness to collaborate?	0	1	2	3
6.2.7	How much does **negotiation of leadership in** a collaborative relationship affect your willingness to collaborate?	0	1	2	3
6.2.8	How much does **lack of incentives for collaboration** influence your willingness to collaborate?	0	1	2	3
6.2.9	How much does **discomfort discussing sensitive topics related to STD and HIV prevention** affect your willingness to collaborate with other organizations?	0	1	2	3

6. 3 Benefits to Cross-border Collaboration: Please describe how much each of the following is a benefit for your organization to work across the Washington, D.C. / Prince George's County border by responding "not at all, very little, somewhat, or a lot"

	BENEFITS	Not at all	Very little	Somewhat	A lot
6.3.1	How much does the **potential for more funding opportunities** influence your willingness to collaborate with another organization?	0	1	2	3
6.3.2	How much does **more efficient use of funding** influence your willingness to collaborate?	0	1	2	3
6.3.3	How much **does improving the quality of services for residents** influence your willingness to collaborate?	0	1	2	3
6.3.4	How much does **potential to increase the number of clients served** influence your willingness to collaborate with other organizations?	0	1	2	3
6.3.5	How much does **expanded reach to special populations** influence your willingness to collaborate with other organizations?	0	1	2	3
6.3.6	How much does **increased credibility with the community** influence your willingness to collaborate with other organizations?	0	1	2	3
6.3.7	How much does **ability to show funders that your organization is supported by other organizations** influence your willingness to collaborate with others organizations?	0	1	2	3
6.3.8	How much does **ability to address equitable funding allocation** influence your willingness to collaborate with other organizations?	0	1	2	3
6.3.9	How much does **increased ability to influence decision-makers** influence your willingness to collaborate with other organizations?	0	1	2	3

6.4 In the past 12 months, have you partnered with another organization across the Washington, D.C. / Prince George's County border to seek funding?

(1) Yes (0) No [CONTINUE TO 6.6]

6.5 Please indicate which organizations you **have partnered with** across the Washington, D.C. / Prince George's County border **to secure grant funding** within the last 12 months. For each organization, please indicate the highest accomplishment level of that partnership: **Discussed**, **Planned**, **Wrote**, **Completed**, **Submitted** or **Awarded**.

Provide name of partner organization	Grant Accomplishment Level

		Discussed	Planned	Wrote	Completed	Submitted	Awarded
6.5.1		1	2	3	4	5	6
6.5.2		1	2	3	4	5	6
6.5.3		1	2	3	4	5	6
6.5.4		1	2	3	4	5	6
6.5.5		1	2	3	4	5	6
6.5.6		1	2	3	4	5	6
6.5.7		1	2	3	4	5	6
6.5.8		1	2	3	4	5	6
6.5.9		1	2	3	4	5	6
6.5.10		1	2	3	4	5	6

6.6 To what extent do you **agree** with the following? Respond by saying, "**strongly disagree**," "**disagree**," "**neither agree nor disagree**," or "**strongly agree**."

		Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
6.6.1	My organization's staff has the **skills needed** to seek cross-border grant funding with another organization.	-2	-1	0	1	2
6.6.2	My organization's staff has a **track record of success and experience necessary** to seek cross-border grant funding with another organization.	-2	-1	0	1	2
6.6.3	There are **enough personnel** at my organization to seek cross-border grant funding with another organization.	-2	-1	0	1	2
6.6.4	My **organization fully supports** seeking cross-border grant funds with another organization.	-2	-1	0	1	2
6.6.5	My organization's **stakeholders support** seeking cross-border grant funds with another organization.	-2	-1	0	1	2

		Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
6.6.6	My organization's **collaborators support** seeking cross-border grant funds with another organization.	-2	-1	0	1	2
6.6.7	My organization has the **resources needed** (i.e. time, equipment, computer software, etc.) to seek cross-border grant funding with another organization.	-2	-1	0	1	2

Section 7: Involvement in Partnerships

In this section, I am going to ask you Yes or No questions to determine your organization's participation level with two organizations. The first set of questions will be about involvement with the Sexually Transmitted Infections Community Coalition (STICC). The second set of questions will be about involvement with the University of Maryland Prevention Research Center (UMD PRC).

7.1 **Sexually Transmitted Infections Community Coalition (STICC)**

Question		Yes [Go to next question]	No
7.1.1	Prior to this interview, were you aware of the Sexually Transmitted Infections Community Coalition, from here on to be referred to as STICC?	1	0 **[Go to 7.2]**
7.1.2	If you are aware of this organization, have you ever considered participating in STICC's activities?	1	0 **[Go to 7.2]**
7.1.3	If you have considered participating in STICC activities, have you ever communicated with this organization about how to become involved?	1	0 **[Go to 7.2]**
7.1.4	If you have communicated with STICC about participation, have you ever attended a regularly scheduled meeting?	1	0 **[Continue]**
7.1.5	Have you ever assisted in planning a STICC event or activity?	1	0 **[Continue]**
7.1.6	Have you ever actively participated in an organization event or activity?	1	0 **[Go to 7.2]**

7.1.7	Have you actively participated in one or more organization events or activities, outside of regularly scheduled meetings?	1	0

7.2 How much has the STICC changed your organization in each of the following ways?

Types of Change		No Influence	Influenced Minor Change	Influenced Major Change
7.2.1	Increased types of services provided	0	1	2
7.2.2	Increased types of clients served	0	1	2
7.2.3	Increased staffing	0	1	2
7.2.4	Increased budget	0	1	2
7.2.5	Increased number of collaborators	0	1	2

7.3 Comments about this change:

_____

_____

7.4 **University of Maryland School of Public Health Prevention Research Center (UMDPRC)**

Question		Yes [Go to next question]	No
7.4.1	Prior to this interview, were you aware of the University of Maryland Prevention Research Center, from here on to be referred to as the UMD PRC?	1	0 **[Go to 7.3]**
7.4.2	If you are aware of the UMD PRC, have you ever considered participating in this organization's activities?	1	0 **[Go to 7.3]**
7.4.3	If you have considered participating in UMD PRC activities, have you ever communicated with this organization about how to become involved?	1	0 **[Go to 7.3]**
7.4.4	If you have communicated with the UMD PRC about participation, have you ever attended a	1	0 **[Continue]**

	regularly scheduled meeting?		
7.4.5	Have you ever planned involvement in a UMD PRC event or activity?	1	0 **[Continue]**
7.4.6	Have you ever actively participated in a UMD PRC event or activity?	1	0 **[Go to 7.3]**
7.4.7	Have you actively participated in one or more UMD PRC events or activities, outside of regularly scheduled meetings?	1	0

7.5 How much has the UMD-PRC changed your organization in each of the following ways?

Types of Change		No Influence	Influenced Minor Change	Influenced Major Change
7.5.1	Increased types of services provided	0	1	2
7.5.2	Increased types of clients served	0	1	2
7.5.3	Increased staffing	0	1	2
7.5.4	Increased budget	0	1	2
7.5.5	Increased number of collaborators	0	1	2

7.6 Comments about this change:

_____

_____

Section 8: Organization Staff and Budget

Identify the number of staff your organization has in each of the following roles. If a staff member has multiple roles, please count them in the role that is their primary role in your organization.

Staff Type		Number of Staff
8.1.1	Overall Planning and Oversight	
8.1.2	Financial Management	
8.1.3	Office Administration	
8.1.4	Human Resources	
8.1.5	Prevention Program Coordination	
8.1.6	Health Education	
8.1.7	Case Management	
8.1.8	Marketing	
8.1.9	Development	
8.1.10	Information Technology	
8.1.11	Program Evaluation	
8.1.12	Clinician	
8.1.13	Research/Science	
8.1.14	Board Development	
8.1.15	Other	
8.1.16	**Total Number of Staff**	

Please indicate the number of your staff who are:

Staff Type		Number of Staff
8.2.1	Paid	
8.2.2	Volunteer	
8.2.3	Part-time	
8.2.4	Full-time	

8.3 Which of the following categories best describes your organization's annual operating budget?

***Remember**, the data you provide will not be connected with your organization name, only by your organization ID number we created for the purposes of this research. Also, any reports written as a result of this data collection will report data in the aggregate.*

(0) 0 - $49,000
(1) $50,000 - $99,999
(2) $100,000 - $249,999
(3) $250,000 - $499,999
(4) $500,000 – 1 million dollars
(5) 1 million – 5 million
(6) 5 million – 10 million dollars
(7) 10 million – 15 million dollars
(8) Over 15 million dollars

8.4 Approximately what percentage of your organization's operating budget was spent on delivering services to residents of Prince George's County over the last 12 months?

(0) 0%
(1) Less than 5%
(2) 5%-10%
(3) 10%-24%
(4) 25%-49%
(5) 50%-74%
(6) 75%-100%
(9) Cannot determine

8.5 Has your budget changed in the last 5 years? (1) Yes [Go to 8.6] (0) No [Go to 8.7]

8.6 If yes, why has your budget changed? _____

8.7 From where do you get most of your HIV prevention funding?

_____

8.8 Approximately what percentage of your HIV prevention funding is

8.8.1	Private	
8.8.2	Public [Go to 8.9 if greater than 0]	

8.9 Approximately what percentage of your **public** funding for HIV prevention is

8.9.1	Federal	
8.9.2	State	
8.9.3	County	
8.9.4	Local	

Section 9: Contact Information

9.1 Please fill out the following information about yourself:

First Name: _____

Last Name: _____

Title: _____

Length of Time in Your Current Position: _____ years _____ months

Email Address: _____

Phone Number: _____

Fax Number: _____

Mobile Phone: _____

Website URL: _____

9.2 How do you prefer to be contacted?

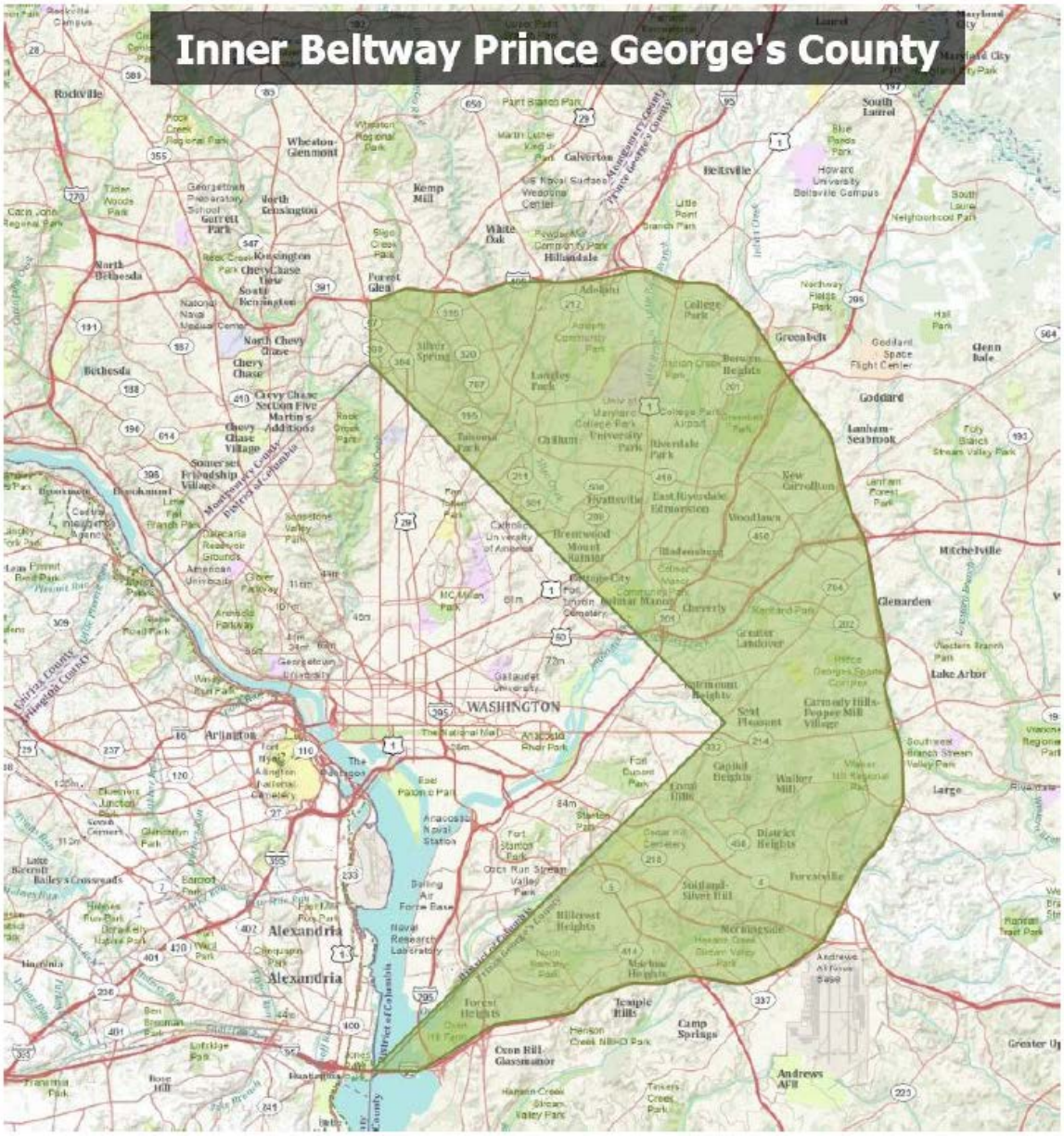
( ) Phone ( ) Email ( ) Text Message ( ) Postal Mail

9.3 If other people participated in the completion of this survey, please provide their information in the table below:

	Name	Title	Length of Time in Position
1.			
2.			
3.			
4.			
5.			
6.			
7.			
8.			
9.			
10.			

Thank you for taking our survey. Your response is very important to us. If you have any comments or concerns regarding this survey, please contact:

Denise Bellows
Faculty Research Assistant
University of Maryland Prevention Research Center
School of Public Health
University of Maryland
301.405.2554
dbellows@umd.edu


Inner Beltway Prince George's County
WASHINGTON
Arlington
Alexandria
Rockville
Bethesda
Silver Spring
Greenbelt
Hyattsville
Mount Rainier
Cheverly
Glenarden
Lake Arbor
Large
Andrews AFB
Camp Springs
Temple Hills
Oxon Hill-Glassmanor
Forestville
District Heights
Suitland-Silver Hill
Morningside
Hillcrest Heights
Fort Washington
Bowie
Laurel
Beltsville
Hillandale
Kensington
Chevy Chase
Wheaton-Glenmont
Kemp Mill
Silver Spring
Takoma Park
Langley Park
Riverdale Park
Greenbelt
Glenn Dale
Lanham-Seabrook
Mitchellville
Bladensburg
Brentwood
Edmonston
Woodlawn
Greater Landover
Seat Pleasant
Capitol Heights
Walker Mill
Carmody Hills-Pepper Mill Village
Fort Dupont Park
Anacostia Naval Station
Bolling Air Force Base
Naval Research Laboratory
Fort Stanton Park
Oxon Run Stream Valley Park
Hensen Creek Stream Valley Park
Andrews Air Force Base
District of Columbia
Prince George's County
Fairfax County
Arlington County
Montgomery County

Appendix C: Original IRB Approved Protocol

UNIVERSITY OF MARYLAND, COLLEGE PARK
Institutional Review Board
Initial Application for Research Involving Human Subjects

Name of Principal Investigator (PI) or Project Faculty Advisor *(NOT a student or fellow)* Bradley O. Boekeloo, PhD **Tel. No** 301-405-8546

Name of Co-Investigator (Co-PI) Nancy L. Atkinson **Tel. No** 301-405-2522

E-Mail Address of PI boekeloo@umd.edu **E-Mail Address of Co-PI** atkinson@umd.edu

Name and address of contact to receive approval documents 2387 Valley Drive, School of Public Health Building Room 1242H College Park, MD 20742

Name of Student Investigator Denise Bellows, Brian Gilchrist **Tel. No.** 301-405-9114

E-Mail Address of Student Investigator dbellows@umd.edu, bwg76@umd.edu

Check here if this is a student master's thesis ☐ **or a dissertation research project** ☐

Department or Unit Administering the Project _____

Project Title UMD-PRC Pilot study: Developing a Prevention Research Information System

Funding Agency: CDC

ORAA Proposal ID Number: 520186

Names of any additional Federal agencies providing funds or other support for this research project:

_____

Target Population: The study population will include (Check all that apply):

- ☐ pregnant women
- ☐ minors/children
- ☐ human fetuses
- ☐ neonates
- ☐ prisoners
- X students
- ☐ individuals with mental disabilities
- ☐ individuals with physical disabilities

Exempt or Nonexempt (Optional): You may recommend your research for exemption or nonexemption by checking the appropriate box below. For exempt recommendation, list the numbers for the exempt category(s) that apply. Refer to pages 6-7 of this document.

☒ **Exempt----List Exemption Category(s)** 2 *Or* ☐ **Non-Exempt**

If exempt, briefly describe the reason(s) for exemption.
Involves diagnostic educational tests. Data collected will not identify human subjects. Disclosure of human subjects' responses will not place the subjects at risk of criminal/civil liability or damage the subjects' financial standing, employability, or reputation.

Date **Signature of Principal Investigator or Faculty Advisor**

Date **Signature of Co-Principal Investigator**

Date **Signature of Student Investigator**

Date **REQUIRED** Departmental Signature
Name _____, **Title** _____
(Please also print name of person signing above)

(PLEASE NOTE: The Departmental signature block should not be signed by the investigator or the student investigator's advisor.)

For Internal Use Only (to be completed by the IRB Office) Application #:

Instructions for Completing the Application

The Departmental Signature block should be signed by the IRB Liaison or Alternate IRB Liaison unless there is a conflict of interest. If the Department or Unit does not have an IRB Liaison, the Department Head, Unit Head or Designee should sign the application.

Please provide the following information in a way that will be intelligible to non-specialists in your specific subject area.

1. **Abstract:** The University of Maryland Prevention Research Center (UMD-PRC) focuses on reducing health disparities in Maryland. The national capital border population in Prince George's County (PGC), Maryland within the "National Capital Beltway" is specifically targeted for community health improvement. This area is predominantly medically underserved and minority. Furthermore, this area suffers from remarkably high rates of primary Syphilis, HIV, stroke, diabetes, low birth weight, and other health problems. Populations in this underserved area work, socialize, and access health care and education in bordering Montgomery County (MC), Maryland and the District of Columbia (DC). The contrasts and similarities between the border population in PGC and the border populations of MC and DC are pronounced in regard to demographics, health services, and health status. The UMD School of Public Health (SPH) happens to be located in Prince George's County at the nexus of these comparisons. Although the SPH has partnered with the City of Seat Pleasant in the underserved area of PGC since 1998, it needs UMD-PRC resources to fully address the glaring need for an infrastructure to link needs with resources in this region. The UMD-PRC infrastructure will build on the triumvirate among the City of Seat Pleasant, the SPH and the Prince George's County Health Department and further engage with organizations within and across the many area borders. It will cross borders to address issues that exacerbate disenfranchisement. The resulting cross-border collaborative will provide new capacity for the region to address shared health problems. A pilot project on HIV and other sexually transmitted infections (STI) exhibits the community-based-participatory-research (CBPR) approach and focuses the UMD-PRC on a health problem disproportionately affecting minorities, and requiring social and systems-level solutions. The pilot examines how to enhance the Prince George's County Health Department, HIV/STI prevention programs through capacity building and collaboration. By developing an online "Prevention Research Information System (PRIS)" that catalogues information on all existing organizations and provides social media resources for collaboration, traditional borders (barriers) will be crossed to deliver educational outreach to individuals at risk, address risk inducing venues, and link areas of need with resources. The PRIS will be developed using community input through various formative research strategies, including focus groups and interviews.
2. **Subject Selection:**

   a. The subjects will be residents of Prince George's County, as well as stakeholders and leaders who work to improve health and reduce incidence of STD/HIV in Prince George's County. Subjects will be recruited through the UMD-Seat Pleasant Health Partnership, the School of Public Health, the Prince George's County Health Department (PGCHD), and the State of Maryland Infectious Disease and Environmental Health Administration (IDEHA)

   b. Subjects will not be selected for any specific characteristics. However, most of our participants will most likely be African American since Prince George's County is predominantly African American. All participants will be age 18 or older. The participants will vary in all other characteristics. As the topic of STD/HIV prevention may be viewed differently by males and females, the researchers will aim to have equal representation of gender in all focus groups. Focus groups for community residents will be conducted separately for males and females. The recruitment strategy for each focus group or interview will be as follows (See also Appendix A):

      A. Foundations and Agencies interested in funding STD/HIV prevention

      Eligibility Criteria:

- Participant(s) must be employed by an agency or organization which currently provides, or has the potential to provide funds for STD/HIV prevention.
- Participant(s) should hold a leadership position in the agency, with some knowledge of funding priorities.
- Participant(s) should be potentially involved in STD/HIV prevention.

Number of Participants: 8-10
Length of focus group/interview: 60-90 minutes
Recruitment Strategy: Ask for representation from funding agencies already known to the PRC, and request their assistance in recruiting other individuals.
Location of focus group/interview: UMD Campus Conference Room

B. Government Agencies
Eligibility Criteria:

- Participant(s) must be a current employee at a government agency
- The government agency must have the ability to directly or indirectly provide services to residents of Prince George's County, Maryland.
- Participant(s) must have been employed at current agency for at least 3 years
- Participant(s) should be potentially involved in STD/HIV prevention.

Number of Participants: 8-10
Length of focus group/interview: 60-90 minutes
Recruitment Strategy: Ask for representation from IDEHA, PGCHD, and others working at government agencies.
Location of focus group/interview: Prince George's County Health Department, Cheverly, MD

C. Medical Clinical Personnel that deal with STD/HIV prevention
Eligibility Criteria:

- Participant(s) must be currently licensed to work with patients
- Participant(s) must be currently employed in a position to provide STD/HIV prevention services to the general public, including but not limited to residents of Prince George's County, Maryland.
- Participant(s) should be potentially involved in STD/HIV prevention.

Number of Participants: 8-10
Length of focus group/interview: 60-90 minutes
Recruitment Strategies: Ask IDEHA and PGCHD to recommend individuals for focus group recruitment
Location of focus group/interview: Prince George's County Health Department, Cheverly, MD

D. CBOs and Non-Profits working with STD/HIV prevention
Eligibility Criteria:

- Participant(s) must be a current employee at a Community-Based Organization (CBO) or Non-Profit agency that has STD/HIV prevention as its primary function.
- The CBO or Non-profit must directly or indirectly provide services to residents of Prince George's County, Maryland.
- Participant(s) must have been employed at current organization for at least two years, and have at least 5 years experience working in the Washington, DC metropolitan area.
- Participant(s) should be potentially involved in STD/HIV prevention.

Number of Participants: 8-10
Length of focus group/interview: 60-90 minutes
Recruitment Strategies: Ask for representation from the Sexually Transmitted Infections Community Coalition (STICC) and others who already have a relationship with the UMD-PRC.
Location of focus group/interview: Prevention Works! (i.e. location of regular STICC meetings)

E. MALE and FEMALE Community Residents

Eligibility Criteria:

- Participants must be male or female, depending on focus group
- Participants must be residents of Prince George's County, for at least 3 years
- Participants can not be students at the University of Maryland,
- Participants must be infected, at-risk, or otherwise impacted by STD/HIV
- Participants must be potential user of STD/HIV prevention information or resources

Number of Participants: 8-10 male; 8-10 female (70% African American, if possible)
Length of Interview: 90 minutes
Recruitment Strategy: Ask members of the STICC to recommend community residents who are "infected, at-risk, or otherwise impacted by STD/HIV," and ask others eligible who have already made contact with the UMD-PRC.
Location of Interview: Community Center

F. University students interested in STD/HIV prevention

Eligibility Criteria:

- Participants must be students at the University of Maryland
- Participants must have evidence of interest and/or experience in STD/HIV prevention

Number of Participants: 8-10 (50/50 male/female)
Length of Interview: 90 minutes
Location of Interview: University of Maryland, College Park campus
Recruitment Strategies:

- Personal email to students who have already expressed interest in STD/HIV prevention and made contact with the UMD-PRC.
- Contact student groups with some related interest in STD/HIV prevention (e.g. Sexual Health And Reproductive Education Student Group, Eta Sigma Gamma, HEAL the Turtle, PHEAR, Student Health Advisory Committee, TERPS for Choice, and the Live Now Campaign)
- Send request over FYI

c. The selection of participants will not include specific characteristics because the aim of the UMD-PRC pilot study is to identify the needs of community members in Prince George's County.

d. Subjects will be recruited to participate in only one focus group or interview.

3. **Procedures:**

Subjects will be asked to participate in a group discussion where they will discuss their perceptions of STD/HIV prevention in Prince George's County and provide feedback about concepts surrounding the development of the Prevention Research Information System (PRIS).

The focus groups will last approximately one and a half hours each. They will be audio-taped, and note takers will be present to document the discussion. The tape and notes will be used to make sure that all comments are recorded properly and to assist in reviewing remarks during the qualitative analysis. Individuals will not be identified in any way during the analysis, and the responses will remain confidential. Participation is completely voluntary – participants may decide not to talk or take part in the discussion at any time. Prior to the focus group, each participant will sign a consent form (see Appendix B) and fill out the attached Demographics Questionnaire (see Appendix C). Participants will receive the "Acknowledgement of Receipt of Incentive" form to review at the beginning of the focus group (Appendix D) and will be asked to sign the form and turn it in after receiving their $20 incentive at the end of the focus group. The focus group moderator will follow the Moderator's Guide (see Appendix E), and will demonstrate the prototype (Appendix F) to be reviewed in each focus group or interview.

4. **Risks and Benefits:** Although there are no direct risks to participants' health and well-being from participation in this study, subjects may experience discomfort or concerns in response to some of the research questions. However, this may be beneficial to some participants to have an outlet to voice their concerns and opinions regarding matters in the community.

   Investigators hope that the data collected through focus groups and interviews will aid in the development of a tool to be used by the community to improve the public health infrastructure and respond to concerns of stakeholders. Specifically, the aims include: 1) Identifying challenges and resources regarding STD/HIV prevention in Prince George's County, 2) Identifying organizations that address STD/HIV in Prince George's County, and 3) Gathering ideas and concerns regarding the development of an online tool for collaboration around STD/HIV prevention in Prince George's County.

   All participants will also receive an incentive valued at $20 as a token of appreciation for their participation.

5. **Confidentiality:** Only the researchers will have access to consent forms and questions. The focus group notes and demographic profiles will not have names of study participants on them and will be kept in a separate location from the consent forms. Prior to the start of the focus groups and interviews, consent forms and response sheets will be coded with matching numbers, so if there is ever a need to identify whether or not a participant signed a consent form, consent forms can be matched to response sheets with the same numerical code. Researchers will delete last names and specific identifying information from audio-recording transcripts of the discussion to protect participant confidentiality. Researchers will not include name or job title in any reports of the focus group discussion. Audio-recordings, transcripts, and researcher notes will be clearly labeled as confidential and kept in a locked file drawer in the Principal Investigator's research unit. Only University of Maryland Prevention Research Center staff will have access to the information. This information will be kept for 10 years and will then be destroyed.

6. **Information and Consent Forms:** The consent form is attached to the IRB package (See Appendix A). Consent forms will only be in the English language. Information in the informed consent form will be explained to participants by the interviewers and focus group moderators prior to the start of the discussion. Participants will be asked to carefully review the consent form and ask questions before they sign it, and prior to any audio-recording and questioning. Participants who have not signed the consent form will not participate in the interview or focus group. All participants will receive a copy of the consent form for their records.
7. **Conflict of Interest:** No conflict of interest.
8. **HIPAA Compliance:** Not Applicable.
9.
   a) **Research Outside of the United States:** Not Applicable.

10. a) **Research Involving Prisoners:** Not Applicable.

A. Foundations and Agencies interested in funding STD/HIV prevention
Identification of Project:
University of Maryland Prevention Research Center
Pilot study: Developing a Prevention Research Information System

Eligibility:
- Participant(s) must be employed by an agency or organization which currently provides, or has the potential to provide funds for STD/HIV prevention.
- Participant(s) should hold a leadership position in the agency, with some knowledge of funding priorities.
- Participant(s) should be potentially involved in STD/HIV prevention.

Purpose: The purpose of this research project is to obtain information about current resources and challenges for STD/HIV prevention in Prince George's County to inform the development of an online tool for identifying STD/HIV resources, and helping STD/HIV organizations better serve community residents.

Procedures: You will be asked to participate in a discussion of approximately 1.5 hours.

Risks: The discussion will be audio recorded.

Confidentiality: Your name will not be matched to information that is recorded in the discussion.

Benefits: Information will be used to develop a tool to improve STI/HIV prevention services in your community. Snacks will be provided, as well as incentives worth approximately $20.

Contact: Questions and Concerns
University of Maryland Prevention Research Center
University of Maryland School of Public Health
College Park, MD 20742
301.405.9114
umdprc@umd.edu

B. Government Agencies
Identification of Project:
University of Maryland Prevention Research Center
Pilot study: Developing a Prevention Research Information System

Eligibility:
- Participant(s) must be a current employee at a government agency
- The government agency must have the ability to directly or indirectly provide services to residents of Prince George's County, Maryland.
- Participant(s) must have been employed at current agency for at least 3 years
- Participant(s) should be potentially involved in STD/HIV prevention.

Purpose: The purpose of this research project is to obtain information about current resources and challenges for STD/HIV prevention in Prince George's County to inform the development of

an online tool for identifying STD/HIV resources, and helping STD/HIV organizations better serve community residents.

Procedures: You will be asked to participate in a discussion of approximately 1.5 hours.

Risks: The discussion will be audio recorded.

Confidentiality: Your name will not be matched to information that is recorded in the discussion.

Benefits: Information will be used to develop a tool to improve STI/HIV prevention services in your community. Snacks will be provided, as well as incentives worth approximately $20.

Contact: Questions and Concerns
University of Maryland Prevention Research Center
University of Maryland School of Public Health
College Park, MD 20742
301.405.9114
umdprc@umd.edu

C. Medical Clinical Personnel that deal with STD/HIV prevention
Identification of Project:
University of Maryland Prevention Research Center
Pilot study: Developing a Prevention Research Information System

Eligibility:

- Participant(s) must be currently licensed to work with patients
- Participant(s) must be currently employed in a position to provide STD/HIV prevention services to the general public, including but not limited to residents of Prince George's County, Maryland.
- Participant(s) should be potentially involved in STD/HIV prevention.

Purpose: The purpose of this research project is to obtain information about current resources and challenges for STD/HIV prevention in Prince George's County to inform the development of an online tool for identifying STD/HIV resources, and helping STD/HIV organizations better serve community residents.

Procedures: You will be asked to participate in a discussion of approximately 1.5 hours.

Risks: The discussion will be audio recorded.

Confidentiality: Your name will not be matched to information that is recorded in the discussion.

Benefits: Information will be used to develop a tool to improve STI/HIV prevention services in your community. Snacks will be provided, as well as incentives worth approximately $20.

Contact: Questions and Concerns
University of Maryland Prevention Research Center
University of Maryland School of Public Health
College Park, MD 20742
301.405.9114

umdprc@umd.edu

D. CBOs and Non-Profits working with STD/HIV prevention
Identification of Project:
University of Maryland Prevention Research Center
Pilot study: Developing a Prevention Research Information System

Eligibility:

- Participant(s) must be a current employee at a Community-Based Organization (CBO) or Non-Profit agency that has STD/HIV prevention as its primary function.
- The CBO or Non-profit must directly or indirectly provide services to residents of Prince George's County, Maryland.
- Participant(s) must have been employed at current organization for at least two years, and have at least 5 years experience working in the Washington, DC metropolitan area.
- Participant(s) should be potentially involved in STD/HIV prevention.

Purpose: The purpose of this research project is to obtain information about current resources and challenges for STD/HIV prevention in Prince George's County to inform the development of an online tool for identifying STD/HIV resources, and helping STD/HIV organizations better serve community residents.

Procedures: You will be asked to participate in a discussion of approximately 1.5 hours.

Risks: The discussion will be audio recorded.

Confidentiality: Your name will not be matched to information that is recorded in the discussion.

Benefits: Information will be used to develop a tool to improve STI/HIV prevention services in your community. Snacks will be provided, as well as incentives worth approximately $20.

Contact: Questions and Concerns
University of Maryland Prevention Research Center
University of Maryland School of Public Health
College Park, MD 20742
301.405.9114
umdprc@umd.edu

E. MALE and FEMALE Community Residents
Identification of Project:
University of Maryland Prevention Research Center
Pilot study: Developing a Prevention Research Information System

Eligibility:

- Participants must be male or female, depending on focus group
- Participants must be residents of Prince George's County, for at least 3 years
- Participants can not be students at the University of Maryland,
- Participants must be infected, at-risk, or otherwise impacted by STD/HIV
- Participants must be potential user of STD/HIV prevention information or resources

Purpose: The purpose of this research project is to obtain information about current resources and challenges for STD/HIV prevention in Prince George's County to inform the development of an online tool for identifying STD/HIV resources, and helping STD/HIV organizations better serve community residents.

Procedures: You will be asked to participate in a discussion of approximately 1.5 hours.

Risks: The discussion will be audio recorded.

Confidentiality: Your name will not be matched to information that is recorded in the discussion.

Benefits: Information will be used to develop a tool to improve STI/HIV prevention services in your community. Snacks will be provided, as well as incentives worth approximately $20.

Contact: Questions and Concerns
University of Maryland Prevention Research Center
University of Maryland School of Public Health
College Park, MD 20742
301.405.9114
umdprc@umd.edu

F. University students interested in STD/HIV prevention
Identification of Project:
University of Maryland Prevention Research Center
Pilot study: Developing a Prevention Research Information System

Eligibility:
- Participants must be students at the University of Maryland
- Participants must have evidence of interest and/or experience in STD/HIV prevention

Purpose: The purpose of this research project is to obtain information about current resources and challenges for STD/HIV prevention in Prince George's County to inform the development of an online tool for identifying STD/HIV resources, and helping STD/HIV organizations better serve community residents.

Procedures: You will be asked to participate in a discussion of approximately 1.5 hours.

Risks: The discussion will be audio recorded.

Confidentiality: Your name will not be matched to information that is recorded in the discussion.

Benefits: Information will be used to develop a tool to improve STI/HIV prevention services in your community. Snacks will be provided, as well as incentives worth approximately $20.

Contact: Questions and Concerns
University of Maryland Prevention Research Center
University of Maryland School of Public Health
College Park, MD 20742
301.405.9114
umdprc@umd.edu

Informed Consent Form

Project Name	**Developmental Focus Groups for Prevention Research Information System (PRIS)**
Participant Age	Study participants must be at least 18 years old, in good health, and wish to be part of a study being done by Bradley Boekeloo, PhD, and Nancy Atkinson, PhD, who are part of the University of Maryland Prevention Research Center in the School of Public Health.
Study Purpose	The purpose of this research project is to obtain information about current resources and challenges for STD/HIV prevention in Prince George's County to inform the development of an online tool for identifying STD/HIV resources, and helping STD/HIV organizations better serve community residents.
Study Activities	The discussion will last about an hour and a half. You will be asked to discuss your opinions and ideas about STD/HIV prevention in Prince George's County Maryland, discuss the concept of an online tool called the Prevention Research Information System (PRIS), and provide feedback on a prototype of this system. You will also be asked to view other websites and give your opinion about whether or not components of other websites will be useful in the PRIS. We, the researchers will take notes and audio-tape the session so we can accurately report your opinions. You will receive a study incentive of $20 for completion of the study.
Confidentiality	We will keep all information collected in this study confidential. Only discuss information in group discussions that you don't mind being shared with others. Also, to protect your confidentiality, only use your first name and the first name of others in group discussions. We will delete last names and specific identifying information from audio-recording transcripts of the discussion to protect your confidentiality. Researchers will not include your name or your job title in any reports of the focus group discussion. Audio-recordings, transcripts, and researcher notes will be clearly labeled as confidential and kept in a locked file drawer in the Principal Investigator's research unit. Only University of Maryland Prevention Research Center staff will have access to the information. This information will be destroyed after ten years.
Risks	There are no expected risks to you if I decide to participate. The only possible risk is if you reveal something in group discussion, which you later regret.
Benefits, Freedom to Withdraw, & Ability to Ask Questions	Although this study is not designed to help you personally, you may benefit by learning about your community. You are free to ask questions, to not answer a particular question, or to stop participating at any time without penalty. If you decide not to participate or do not want to answer some questions, it will not affect your relationship with any researchers at the University of Maryland-Prevention Research Center.
Contact Information of Researchers	University of Maryland, College Park, MD, 20742 Bradley Boekeloo, PI — Telephone: 301-405-8546 — Email: boekeloo@umd.edu Nancy L. Atkinson, Co-PI — Telephone: 301-405-2522 — Email: atkinson@umd.edu
Contact Information of Institutional Review Board	If you have questions about your rights as a research subject or wish to report a research-related injury, please contact: **Institutional Review Board Office, University of Maryland, College Park, Maryland, 20742; (e-mail) irb@deans.umd.edu; (telephone) 301-405-4212**

Print Name _____

Signature _____

Date_____

Demographic questionnaire

Focus Group Date: ____/___/____

Time: ___:_____AM PM

Location: _____

Gender: Male Female **Age**: _____

Ethnicity: Hispanic Non-Hispanic

What is your race? Pick as many as apply to you.

- ☐ Asian
- ☐ American Indian/Alaska Native
- ☐ Black or African American
- ☐ Native Hawaiian or other Pacific Islander
- ☐ White
- ☐ I choose not to answer
- ☐ Other (please specify: _____)

City/Town of current ***residence***: _____ **Zip code**: _____

City/Town of current ***employment***: _____ **Zip code**: _____

Median Household Income:

- $15,000 or less
- $15 – 25,000
- $25 – 45,000
- $45 – 65,000
- $65 – 100,000
- $100,000 +

Number of people in household:

- 1
- 2
- 3
- 4
- 5 +

Do any children under the age of 18 live in your household? Yes No

Employment status:

- Unemployed
- Part-time employed
- Full-time employed
- Student (unemployed)
- Student (employed part-time)
- Student (employed full-time)

Occupation:

- Education
- Government
- Health Service/Health Care
- Service/Hospitality
- Technical/Trade
- Other (please specify:_____

Marital Status:

- Single
- Separated
- Divorced
- Married/Partnered
- Widowed

Level of education:

- High School or less
- Trade school/vocational school
- Associates degree (2-year program)
- College degree (4-year program)
- Graduate degree
- Other Advanced degree (M.D., J.D., Ph.D., etc.

University of Maryland Prevention Research Center
Acknowledgment of Receipt of Incentive

Please complete the information below to receive the $20 incentive for participating in this focus group or interview. This information will **NOT** be used to identify you or any information you have shared with us. This information is being collected **ONLY** to acknowledge that you have received the promised incentive.

This is to acknowledge that I received $20.00 (twenty dollars) for participating in the focus group/interview for the University of Maryland Prevention Research Center.

Name: _____

Address: _____

Social Security #:_____-_____-_____

Signature: _____

Date: _____

Please select any of the boxes below that apply to you:

☐ I would like to receive information about the findings from this focus group/interview.

☐ I would like to participate in a group/interview like this again.

☐ I would like to serve as a volunteer "community advisor" in the future.

If you checked any of the boxes above, please provide your e-mail address and/or phone number.

_____ _____
E-mail Address Phone Number

Staff Person Distributor:

_____

Staff Person Witness:

_____

Moderator's Guide

A = Foundations and Agencies interested in funding STD/HIV prevention
B = Government Agencies
C = Medical Clinical Personnel that deal with STD/HIV prevention
D = CBOs and Non-Profits working with STD/HIV prevention
E = MALE and FEMALE Community Residents
F = University students interested in STD/HIV prevention

***Introduction* (5 minutes)**
We would like to thank you in advance for your participation in this (FOCUS GROUP OR INTERVIEW). I will begin by asking everyone to turn off cellular phones, pagers, and any other audible device, as this focus group will be audio recorded. My name is (MODERATOR NAME), and I will be leading the discussion. This is (NAME), and s/he will be taking notes. This is (NAME), and s/he will be monitoring the discussion as well. We are with the University of Maryland Prevention Research Center. You have been gathered here today because you (*select for appropriate focus group)*

A. [are all **agencies** who have the ability to provide **funding** and resources for STD/HIV prevention programs that service individuals who live or work in Prince George's County, Maryland].
B. [work for a **government agency** that may provide STD/HIV prevention services to individuals who live or work in Prince George's County, Maryland.]
C. [are all **medical personnel**, who provide STD/HIV prevention services to individuals who live or work in Prince George's County, Maryland.]
D. [are all representatives of **organizations**, who provide STD/HIV prevention services to individuals who live or work in Prince George's County, Maryland]
E. [are all **residents** Prince George's County, and we are interested in your perceptions of STD/HIV prevention services in Prince George's County, Maryland]
F. [are all **students** at the University of Maryland who have expressed interest in STD/HIV prevention.]

We are interested in your perceptions of STD/HIV prevention in Prince George's County, Maryland. We would also like to get your feedback about an idea we have to create an online system to increase partnership and collaboration between funding agencies, government health departments, academics, CBOs and other organizations who do STD/HIV prevention work. The overall goal is to increase the effectiveness of STD/HIV prevention in Prince George's County neighborhoods with high STD/HIV incidence rates. In particular, we are focusing on neighborhoods within the National Capital Beltway.

This focus group will last approximately one and a half hours. It will be audio-taped, and note takers are present to document the discussion. The tape and notes will be used to make sure that we record all of your comments (in your own words) and to assist us in reviewing your remarks during the analysis of this focus group. You will not be identified in any way during the analysis, and the responses you provide will remain confidential. Your participation is completely voluntary. You may decide not to talk or take part in the discussion at any time. If you decide to leave, please keep all responses you heard here confidential.

[*FOCUS GROUP ONLY*: Please respect other individuals' opportunities to respond to each question. Allow one person to speak at a time without interruption.]

There are no right or wrong answers. **Your opinions, thoughts, and suggestions are extremely valuable to our research**. We encourage honest participation. Please feel free to respond to the question(s) to which you have a valuable response, [*FOCUS GROUP ONLY]* especially if you have a view or opinion different from others in the group. I would just like to ask that you speak one at a time and that everyone participate.

- [Does anyone/Do you] have any questions about this process before we begin?

Answer and take note of any questions before moving forward

I am going to begin the audio recording now.

Start tape now. For each of the following questions, ask participants to respond with yes or no. Do not proceed with recording until everyone has responded "yes."

- Has everyone here been informed about this research and had the opportunity to ask questions prior to this recording?
- Has everyone here signed a written consent form about this focus group, and consented to being audio recorded?
- Has everyone completed the brief, anonymous demographic questionnaire?

[FOCUS GROUPS ONLY] ***Warm-up***
To start, let's go around and have everyone introduce themselves with first names only or a chosen pseudonym. Also, please tell us where you are from.]

Open-ended Questions
[E, F ONLY
Prince George's County Maryland is the 2nd leading jurisdiction in Maryland, (behind Baltimore City), with persons infected with HIV/AIDS. The county also ranks 2nd behind Baltimore in cases of syphilis, gonorrhea, and chlamydia. STD rates in Prince George's County are 5-6 times greater than in Montgomery County. Between July 2004 and June 2005, 89% of new AIDS cases in Prince George's County occurred in African Americans. Prince George's County has identified sexual risks as priority health concerns for the county. **]**

This discussion will focus on preventing STD/HIV in Prince George's County. To clarify, "STD/HIV prevention," includes anything that would encourage safe sex practices, reduce infections or identify the need for treatment. Screening for STDs, HIV testing, condom distribution and educational information about STD/HIV are all examples of STD/HIV prevention. Clinical and medical treatment of infection is not included in this description. Organizations could provide this prevention through formal education, advertisements, public service announcements, screening opportunities, brochures, fliers, activities, entertainment events, health fairs, etc.

Do you have any questions about what I am referring to when I say, "STD/HIV prevention?

Address any questions before moving on to the next section

I. CHALLENGES AND OPPORTUNITIES FOR STD/HIV PREVENTION (10 MINUTES)

In the first part of this discussion, we would like you to discuss the challenges and opportunities for STD/HIV prevention in Prince George's County.

- What do you think are the challenges to STD/HIV prevention in Prince George's County, Maryland? *List challenges on white board or flip chart*
  - What makes it difficult for people to get HIV testing/screening, sexual risk and protection information, etc.?
- What could be done to overcome these challenges?
  - What do you think the community could do to make it easier for people to get STD/HIV prevention resources, information, or services?
  - What do you think it would take for people in your community to use existing STD/HIV programs?
- What opportunities exist in Prince George's County?
  - What is going on that could be built upon to improve STI/HIV prevention efforts? How about in other nearby communities?
  - Who is doing important work in the county that could be supported and expanded?

II. IDENTIFICATION OF STD/HIV PREVENTION ORGANIZATIONS (10 MINUTES)

For this next part of the [focus group/interview], I would like you to identify as many organizations providing STD/HIV prevention services as you can.

- Where do you think people usually get information about STD/HIV prevention?
- What organizations do you know of that provide STD/HIV prevention in Prince George's County? Remember, organizations can be small or large, local, national or international. They may be physically present in the local area or affect Prince George's County through the internet, mass media, etc.
- Which organizations do you know of that could provide STD/HIV prevention in Prince George's County if they had the motivation and resources?
- What organizations not located in Prince George's County do you know of that could provide STD/HIV prevention to Prince George's County residents?

Add questions for the following groups:

For A and B only:

- Which types of organizations would you make a high priority for supporting in this regard?

For C and D only:

- What organizations in neighboring jurisdictions are doing a good job in STD/HIV prevention? How could they help organizations in Prince George's County do a better job?

III. BENEFITS AND CHALLENGES OF COLLABORATION (15 minutes)
[only for groups A, B, C, D]

- How would organizations benefit from organizational collaborations?
- How would residents benefit?
- What are the challenges to organizational collaboration?
- What makes organizational collaboration difficult?
- What would make organizational collaboration easier?

IV. CONCEPTION OF AN ONLINE STD/HIV PREVENTION INFORMATION SYSTEM (15 MINUTES)

We have received funding to design an online system designed to increase collaboration between organizations and build capacity within organizations. The system would also be designed to catalog all STD/HIV prevention resources available to residents of Prince George's County, Maryland and provide an online space for community residents.

- What do you think about the idea of a Prevention Research Information System?
- Does anything like this already exist, that you know of?
- Which types of services would you want to be part of this system: STD/HIV prevention outreach, STD/HIV prevention education, STD/HIV testing and counseling sites, substance abuse and mental health, family planning, others?

If there was a website that cataloged STD/HIV prevention resources in Prince George's County, Maryland,

A. [How could funding agencies use this site?]
   a. How could it help funders to link with these organizations?
   b. As a funding agency, what kind of information would you want on this website?
   c. What would make it more likely that funders would utilize this website? What would make it less likely?
B. [How could government agencies use this site?]
   a. What kind of data collection would you want to see on this site?
   b. What would you want to know about STD/HIV prevention organizations?
C. [How could medical personnel use this site?]
   a. What information would you want your patients to have available to them?
   b. What kinds of resources would you want to provide to your patients through this site?
D. [How could CBOs use this site?]
   a. Would it be helpful to learn about other organizations working on STD/HIV prevention in your community?
   b. What kinds of information would you like to see on this site?
   c. What kinds of tools would be useful to you and your organization?
E. [How could community residents use this site?]
   a. What kind of information would be useful to you?
   b. What kind of web tools (i.e. blogs, message boards, events calendar, chat feature, etc.) would you like to see on the site?
F. [How could university students use this site?]
   a. What kind of information would you like to see on the site?
   b. How could you use this site to link with STD/HIV prevention organizations?

V. PROTOTYPE PRE-TEST (30 MINUTES)

We have identified potential prototypes of what this Prevention Research Information System might look like. As I show you these prototypes, I will ask you some questions. Please feel free to stop me or ask me to go back to a section we have already passed and share any thoughts, concerns or questions you may have. This is a lot of new

information so feel free to take time to process everything before you come up with questions.

Here are some examples of websites that provide certain functions which might be helpful in the development of PRIS. Please let us know your opinion of each of these as we go through them.
For each site, ask:

- What is your opinion about this web feature/tool?
- What (if anything) about this feature/tool would be beneficial in providing STD/HIV prevention resources?

[A-F] Web 2.0 which might be useful for organizations to showcase their work, or for community residents to express thoughts, concerns or ideas…
http://www.abovetheinfluence.com/speak/default.aspx?path=nav

[A-F] Map allows one to "Define your community" and find services in defined community. http://www.findyouthinfo.gov/default.aspx

[A-F] Resource of online tools for organizations www.innonet.org

[A-D Only] Nice home page – clear about goals and who site is for. Also, "join our community" link to a wiki. http://www.preventionworks.org/index.php

[E, F Only] Site for general public with section for "parents and teachers"
http://teens.drugabuse.gov/

[A, B, C, D Only]

- How would you feel about registering on a website so that the website could provide you with information on your specific interests and needs?
- How would you feel about having to log into a website each time you used it?

VI. Closure *(5 minutes)*

- Do you have any other ideas for improving STD/HIV prevention in Prince George's County?
- Do you have any final thoughts, concerns, questions or suggestions for the Prevention Research Information System (PRIS)?

Thank you for helping us out with this [focus group/interview] today! Your input has been very informative and will assist us in improving STD/HIV prevention efforts in your community. Please don't forget to take your incentive before you leave.

Appendix D: IRB Approval Letter for All Study Data Collection

UNIVERSITY OF MARYLAND
INSTITUTIONAL REVIEW BOARD

1204 Marie Mount Hall
College Park, MD 20742-5125
TEL 301.405.4212
FAX 301.314.1475
irb@umd.edu
www.umresearch.umd.edu/IRB

DATE:	January 23, 2014
TO:	Bradley Boekeloo, PhD
FROM:	University of Maryland College Park (UMCP) IRB
PROJECT TITLE:	[408031-2] IRB Protocol: 10-0106 - UMD-PRC Pilot study: Developing a Prevention Research Information System
REFERENCE #:	10-0106
SUBMISSION TYPE:	Continuing Review/Progress Report
ACTION:	APPROVED
APPROVAL DATE:	January 23, 2014
EXPIRATION DATE:	February 7, 2015
REVIEW TYPE:	Expedited Review
REVIEW CATEGORY:	Expedited review category # *8 (a) (c)*

Thank you for your submission of Continuing Review/Progress Report materials for this project. The University of Maryland College Park (UMCP) IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received Expedited Review based on the applicable federal regulation.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Federal regulations require each participant receive a copy of the signed consent document.

Please note that any revision to previously approved materials must be approved by this committee prior to initiation. Please use the appropriate revision forms for this procedure which are found on the IRBNet Forms and Templates Page.

All UNANTICIPATED PROBLEMS involving risks to subjects or others (UPIRSOs) and SERIOUS and UNEXPECTED adverse events must be reported promptly to this office. Please use the appropriate reporting forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office.

This project has been determined to be a Minimal Risk project. Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for this procedure. Your documentation for continuing review must be received with sufficient time for review and continued approval before the expiration date of February 7, 2015.

Please note that all research records must be retained for a minimum of three years after the completion of the project.

If you have any questions, please contact the IRB Office at 301-405-4212 or irb@umd.edu. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of Maryland College Park (UMCP) IRB's records.

Appendix E: Results of Keyword searches in MeSH Terms Database

Keyword	**Mesh Terms** Searched PubMed MeSH Terms http://www.ncbi.nlm.nih.gov/mesh/
Theoretical Framework	
Health Service Utilization Model	"No items found" However, consider that Health Service Accessibility, *Search date: October 5, 2014*
Health Service	Community Health Service: Diagnostic, therapeutic and preventive health services provided for individuals in the community. *Year introduced: 1967(1965)*
Availability *Search date: Sept. 26, 2014* 23 results: Biological availability, nutritive value, ***health services accessibility***, supply and distribution, sequestering agents, ***healthcare disparities***, Hypoxia-Inducible Factor 1, Vascular Endothelial Growth Factor Receptor-1, Iron Regulatory Protein 1, Serotonin Syndrome, Haemophilus influenzae type b, Receptors, Glucagon, ***health manpower***, ***Community Health Workers***, PhoQ protein, E coli, NPC2 protein, Drosophila, Pap31 protein, Bartonella bacilliformis, PhoP protein, E coli, ccm1 protein, Chlamydomonas reinhardtii, iron response regulator protein, Bacteria, rosiglitazone, U93385, Inzolen	Health Service Accessibility: The degree to which individuals are inhibited or facilitated in their ability to gain entry to and to receive care and services from the health care system. Factors influencing this ability include geographic, architectural, transportational, and financial considerations, among others. Year introduced: 1978 Healthcare disparities: Differences in access to or availability of medical facilities and services. Year introduced: 2008 Health Manpower The availability of HEALTH PERSONNEL. It includes the demand and recruitment of both professional and allied health personnel, their present and future supply and distribution, and their assignment and utilization. Year introduced: 1968 Community Health Workers Persons trained to assist professional health personnel in communicating with residents in the community concerning needs and availability of health services. Year introduced: 1971
Accessibility 11 Results: ***Health Service Accessibility;*** Architectural Accessibility; Chromatin Assembly and Disassembly; HMG-	Health Service Accessibility: The degree to which individuals are inhibited or facilitated in their ability to gain entry to and to receive care and services from the health care system. Factors influencing this ability include ***geographic***,

Box Domains; ***Community Health Planning; Health Care Quality, Access, and Evaluation;*** Optical Storage Device; ***Medically Underserved Area;*** Biological Availability; CHRAC-16 protein; Drosophila [supplementary concept] *Search Date: Sept. 21, 2014*	***architectural***, ***transportational***, and ***financial considerations***, among others. Year introduced: 1978 Community Health Planning: Planning that has the goals of improving health, improving accessibility to health services, and promoting efficiency in the provision of services and resources on a comprehensive basis for a whole community. (From Facts on File Dictionary of Health Care Management, 1988, p299) Year introduced: 1995 Health Care Quality, Access and Evaluation: The concept concerned with all aspects of the quality, accessibility, and appraisal of health care and health care delivery. Year introduced: 1998 Medically Underserved Area: A geographic location which has insufficient health resources (manpower and/or facilities) to meet the medical needs of the resident population. Year introduced: 1978
Accessibility of health services[2] 1 result *Search Date: Sept. 21, 2014*	1 result: "Health Service Accessibility" Same as below
Access to health care[2] 1 result *Search Date: Sept. 21, 2014*	1 result: "Health Service Accessibility" *See Health Services Accessibility, under Availability and Accessibility* Indexed under Delivery of healthcare. Includes: *health care rationing, health facility closure, health facility environment, health facility size, marketing of health services, social marketing.*
Acceptability 1 result *Search Date: Sept. 21, 2014*	1 Result: Patient Acceptance of Health Care: The seeking and acceptance by patients of health service. *Year introduced: 1975* Previously indexed under attitude to health; healthcare quality, access and evaluation; Terms included in *Patient Acceptance of Healthcare*: *Patient compliance; medical adherence; patient participation; patient satisfaction;*

[2] When typing "health" into the MeSH search bar, the following terms are suggested: *Abuse of health services,* ***acceptability of health care, access to health care, accessibility of health services, accountable health plan(s),*** *acquisition(s) health facility, administration health facility/services, administrator(s) health facility/services, adolescent health service(s), advance healthcare planning,* ***agency (ies) health systems***

	patient preference; treatment refusal
Acceptability of health care[2] 1 result *Search Date: Sept. 21, 2014*	Patient acceptance of Health Care: The seeking and acceptance by patients of health service. *Year introduced: 1975* (indexed under *attitude to health – delivery of health care*; under this category are *patient compliance*, *medical adherence*, *patient satisfaction*)
Accountability 2 Results *Search Date: Sept. 21, 2014*	2 Results: Social Responsibility; Health Insurance Portability and Accountability Act Neither really relate to the definition of accountability described by the model.
Accountable health plan(s)[2] 1 result	Managed Competition: A strategy for purchasing health care in a manner which will obtain maximum value for the price for the purchasers of the health care and the recipients. *The concept was developed primarily by Alain Enthoven of Stanford University and promulgated by the Jackson Hole Group.* The strategy depends on sponsors for groups of the population to be insured. The sponsor, in some cases a health alliance, acts as an intermediary between the group and competing provider groups (accountable health plans). The competition is price-based among annual premiums for a defined, standardized benefit package. (From Slee and Slee, Health Care Reform Terms, 1993) *Year introduced: 1996*
Research Question	
HIV/AIDS Prevention *Search date Oct. 1 2014*	No results (not even HIV prevention or AIDS prevention)
Agency 40 results: *United States Agency for Healthcare Research and Quality, United States Environmental Protection Agency, United States Agency for International Development, Home Care Agencies,* ***Voluntary Health Agencies, Health Systems Agencies****, United States Social Security Administration, International Agencies,* ***Government Agencies****, Diagnostic Test Approval, Off-Label Use, Limnology,*	Government agency: Administrative units of government responsible for policy making and management of governmental activities. *Year introduced: 1968* Health systems agency: Health planning and resources development agencies which function in each health service area of the United States (PL 93-641). *Year introduced: 1978* Voluntary health agency: Non-profit organizations concerned with various aspects of health, e.g., education, promotion, treatment, services, etc. Public-Private Sector Partnerships: An organizational enterprise between a public

Public-Private Sector Partnerships*, Peace Corps, Cultural Competency, Personhood, Vocabulary Controlled, Device Approval, United States National Aeronautics and Space Administration, Investigational New Drug Application, Drug Approval, Technical Report, Private Hospitals, World Health Organization, United States Food and Drug Administration, United States Federal Trade Commission, United States Substance Abuse and Mental Health Services Administration, Religion, Pan American Health Organization, Nursing Staff, National Library of Medicine (U.S.), National Institutes of Health (U.S.), National Academy of Sciences (U.S.), Medical Staff, Inservice Training, Heptachlor, Health Systems Plans, Dental Staff, Centers for Disease Control and Prevention (U.S.), 17-methylepithiostanol*	sector agency, federal, state or local, and a private sector entity. Skills and assets of each sector are shared to deliver a service or facility for the benefit or use of the general public. *Year introduced: 2009*
Organization 23 results: ***Organization and Administration****,* ***Organizations****,* ***organization and administration [Subheading]****,* *World Health Organization, Pan American Health Organization, Professional Review Organizations,* ***Nonprofit Organizations****, Hospital-Physician Joint Ventures, Accountable Care Organizations, Management Service Organizations, Health Planning Organizations,* ***Provider-Sponsored Organizations****, United Nations,* ***Societies****, Preferred Provider Organizations, Hospital Personnel Administration****,*** *Hospital Administration, Health Maintenance Organizations, Consumer Organizations, Computer Systems, Health Level Seven, Tango7 protein, Drosophila [Supplementary Concept], World Health Organization oral rehydration solution [Supplementary Concept]*	Organization and Administration: The planning and managing of programs, services, and resources. *Year introduced: 1968.* Organization and administration [Subheading]: Used for administrative structure and management. *Year introduced: 1978* Organizations: Administration and functional structures for the purpose of collectively systematizing activities for a particular goal. *Year introduced: 1968* Nonprofit Organizations: Organizations which are not operated for a profit and may be supported by endowments or private contributions. *Year introduced: 1982* Provider-Sponsored Organizations: Entities sponsored by local hospitals, physician groups, and other licensed providers which are affiliated through common ownership or control and share financial risk whose purpose is to deliver health care services. *Year introduced: 1999*

	Societies: Organizations composed of members with common interests and whose professions may be similar.
Coordination of services 4 results: ***Centralized Hospital Services, Organization and Administration, Case Management,*** *Team Nursing* *Search date: Oct. 5, 2014*	Centralized Hospital Services: The coordination of services in one area of a facility to improve efficiency. *Year introduced: 1991(Aug 1977)* Organization and Administration: The planning and managing of programs, services, and resources. *Year introduced: 1968* Case Management: A traditional term for all the activities which a physician or other health care professional normally performs to insure the coordination of the medical services required by a patient. It also, when used in connection with managed care, covers all the activities of evaluating the patient, planning treatment, referral, and follow-up so that care is continuous and comprehensive and payment for the care is obtained. (From Slee and Slee, Health Care Terms, 2nd ed) *Year introduced: 1996* Team Nursing: Coordination of nursing services by various nursing care personnel under the leadership of a professional nurse. The team may consist of a professional nurse, nurses' aides, and the practical nurse. *Year introduced: 1967(1965)*
Coordinated HIV Prevention *Search date: Oct. 5, 2014*	No results
Coordinated 26 results; 6 of which were non-biological/medical and may relate to the definition of "coordinated" used in this study. *Search date: Oct. 5, 2014*	Parish Nursing: A nursing specialty involving programs designed to bring wholeness and healing to a particular faith community through addressing the health needs of body, mind, and spirit. They are coordinated by registered NURSES and may involve HEALTH EDUCATION and counseling, facilitation, referral, PATIENT ADVOCACY, and health care plan interpretation, as influenced and defined by the unique needs of the congregation. *Year introduced: 2014* Pain Management: A form of therapy that employs a coordinated and interdisciplinary approach for easing the suffering and improving the quality of life

	of those experiencing pain. *Year introduced: 2012* Critical Pathways: Schedules of medical and nursing procedures, including diagnostic tests, medications, and consultations designed to effect an efficient, coordinated program of treatment. (From Mosby's Medical, Nursing and Allied Health Dictionary, 4th ed) *Year introduced: 1996* Home Care Services: Community health and NURSING SERVICES providing coordinated multiple services to the patient at the patient's homes. These home-care services are provided by a visiting nurse, home health agencies, HOSPITALS, or organized community groups using professional staff for care delivery. It differs from HOME NURSING which is provided by non-professionals. *Year introduced: 1967* Medicare: Federal program, created by Public Law 89-97, Title XVIII-Health Insurance for the Aged, a 1965 amendment to the Social Security Act, that provides health insurance benefits to persons over the age of 65 and others eligible for Social Security benefits. It consists of two separate but coordinated programs: hospital insurance (MEDICARE PART A) and supplementary medical insurance (MEDICARE PART B). (Hospital Administration Terminology, AHA, 2d ed and A Discursive Dictionary of Health Care, US House of Representatives, 1976) *Year introduced: 1991* Community Psychiatry Branch of psychiatry concerned with the provision and delivery of a coordinated program of mental health care to a specified population. The foci included in this concept are: all social, psychological and physical factors related to etiology, prevention, and maintaining positive mental health in the community. *Year introduced: 1980*
Cooperation 16 results: *Lymphocyte Cooperation,* ***International Cooperation, Public-Private Sector Partnerships,*** *Patient Compliance, Cell-in-Cell Formation, Medication Adherence, United Nations, T-Lymphocytes,* ***Hospital Shared Services,***	International Cooperation: The interaction of persons or groups of persons representing various nations in the pursuit of a common goal or interest. Public-Private Sector Partnerships: An organizational enterprise between a public sector agency, federal, state or local, and a private sector entity. Skills and assets of each sector are shared to deliver a service or facility for the benefit or use of the

T-Lymphocytes, Helper-Inducer, B-Lymphocytes, Antigens, T-Independent, Histocompatibility Antigens Class II, Tead1 protein, zebrafish, Par-1 protein, Xenopus, Mid1 protein, S pombe *Search date: Oct. 5, 2014*	general public. *Year introduced: 2009* Hospital Shared Services: Cooperation among hospitals for the purpose of sharing various departmental services, e.g., pharmacy, laundry, data processing, etc. *Year introduced: 1972(1968)*
Collaboration 1 result, but "See also Community Networks" *Search date: Oct. 5, 2014*	Cooperative Behavior: The interaction of two or more persons or organizations directed toward a common goal which is mutually beneficial. An act or instance of working or acting together for a common purpose or benefit, i.e., joint action. (From Random House Dictionary Unabridged, 2d ed) *Year introduced: 1973(1971)* Community Networks: Organizations and individuals cooperating together toward a common goal at the local or grassroots level. *Year introduced: 1996*
Barriers[3] 21 results; only 3 potentially relevant in some way *Search date: Oct. 5, 2014*	Communication Barriers: Those factors, such as language or sociocultural relationships, which interfere in the meaningful interpretation and transmission of ideas between individuals or groups. *Year introduced: 1991(1979)* Health Services for Transgendered Persons: Access to specialized care for transgendered populations. Health systems organized to take account of the special healthcare needs of marginalized groups who may face barriers in accessing health services. (http://www.who.int/reproductivehealth/topics/linkages/guidance_package.pdf) *Year introduced: 2013* Social Isolation: The separation of individuals or groups resulting in the lack of or minimizing of social contact and/or communication. This separation may be accomplished by physical separation, by social barriers and by psychological mechanisms. In the latter, there may be interaction but no real communication. *Year introduced: 1969*

[3] "Barriers to healthcare" returned no results; "Barriers to health" and "barriers to services" resulted in one result, "Health Services for Transgendered Persons."

Challenges 31 results; only 2 were possibly relevant *Search date: Oct. 5, 2014*	Entrepreneurship: The organization, management, and assumption of risks of a business or enterprise, usually implying an element of change or challenge and a new opportunity. *Year introduced: 1992* Risk-Taking: Undertaking a task involving a challenge for achievement or a desirable goal in which there is a lack of certainty or a fear of failure. It may also include the exhibiting of certain behaviors whose outcomes may present a risk to the individual or to those associated with him or her. *Year introduced: 1979(1975)*
Organizational barrier *Search date: Oct. 5, 2014*	No results
Border-related barrier *Search date: Oct. 5, 2014*	No results
Metropolitan 4 results: ***Urban hospitals, Local government, Urban population, Cities*** See also: *Metropolitan hospitals, Metropolitan government* *Search date: Oct. 5, 2014*	Urban Hospitals: Hospitals located in metropolitan areas. *Year introduced: 1991(1986)* Local Government: Smallest political subdivisions within a country at which general governmental functions are carried-out. *Year introduced: 1999* Urban Population: The inhabitants of a city or town, including metropolitan areas and suburban areas. *Year introduced: 1968* Cities: A large or important municipality of a country, usually a major metropolitan center. *Year introduced: 1998* Metropolitan hospitals: *See "Urban Hospitals" above* Metropolitan government: *See "Local Government" above*
Urban 19 results: ***Urban Health Services***, *Urban Renewal,* ***Urban Health, Urban Population, Urban Hospitals, Population Dynamics***, *City Planning,* ***Urbanization, Cities***, *Prader-Willi*	Urban Health Services: Health services, public or private, in urban areas. The services include the promotion of health and the delivery of health care. *Year introduced: 1996* Urban Health: The status of health in urban populations.

habitus, osteopenia, and camptodactyly [Supplementary Concept], Anthracosis, Vitamin A Deficiency, Street Drugs, ***Poverty Areas****, Physician Assistants, Chancroid, Architecture as Topic, Cutis Laxa With Severe Pulmonary, Gastrointestinal, And Urinary Abnormalities [Supplementary Concept], Urban Schosser Spohn syndrome [Supplementary Concept]*	*Year introduced: 1990(1979)* Urban Population: The inhabitants of a city or town, including metropolitan areas and suburban areas. *Year introduced: 1968* Hospitals, Urban: Hospitals located in metropolitan areas. *Year introduced: 1991(1986)* Population Dynamics: The pattern of any process, or the interrelationship of phenomena, which affects growth or change within a population. *Year introduced: 1976* Urbanization: The process whereby a society changes from a rural to an urban way of life. It refers also to the gradual increase in the proportion of people living in urban areas. *Year introduced: 1968* Cities: A large or important municipality of a country, usually a major metropolitan center. *Year introduced: 1998* Poverty Areas: City, urban, rural, or suburban areas which are characterized by severe economic deprivation and by accompanying physical and social decay. *Year introduced: 1991(1980)*
Border Theory	
State border *Search date Oct. 1-2, 2014*	no results
Jurisdictional border *Search date Oct. 1-2, 2014*	no results
Political border *Search date Oct. 1-2, 2014*	no results
Borderline *Search date Oct. 1-2, 2014*	no relevant results
Boundary *Search date Oct. 1-2, 2014*	no relevant results
Border – 60 results, only one of which was relevant: ***emigration and immigration****.* The rest were related to a congenital disease in sheep called "border disease," and various anatomical parts.	Emigration and Immigration:[4] the process of leaving one's country to establish residence in a foreign country *Year introduced: 1963*

[4] Decided to look up mesh terms related to emigration and immigration. Found Human Migration, Transients, and Migrants. Search for "Border crossing" also resulted in Emigration and immigration

Search date Oct. 1-2, 2014	
Human Migration 4 other results, unrelated *Search date Oct. 2 2014*	Human Migration: Periodic movement of human settlement from one geographic location to another. *Year introduced: 2013*
Transients and migrants *Search date Oct. 2 2014*	People who frequently change their place of residence
Borders as a barrier to health *Search date: Oct. 5, 2014*	No results
Borders as a barrier to HIV prevention *Search date: Oct. 5, 2014*	No results
Border-based discrimination and disparity *Search date: Oct. 5, 2014*	No results
Cultural differences No results; however, "cultural competency" was identified through a search on "agency"	Cultural Competency (identified through "agency" search): Cultural and linguistic competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations. Competence implies the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities. *Year introduced: 2008*
Cultural 13 results; 12 of which were relevant. Body modification was not relevant. *Search date: Oct. 5, 2014*	Culture: A collective expression for all behavior patterns acquired and socially transmitted through symbols. Culture includes customs, traditions, and language. Cultural Competency: Cultural and linguistic competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations. Competence implies the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities. *Year introduced: 2008* Cultural Diversity: Coexistence of numerous distinct ethnic, racial, religious, or cultural groups within one social unit, organization, or population. (From American Heritage Dictionary, 2d college ed., 1982, p955)

	Year introduced: 1996 Cultural Evolution: The continuous developmental process of a culture from simple to complex forms and from homogeneous to heterogeneous qualities. Year introduced: 1991(1978) Cultural Deprivation: The absence of certain expected and acceptable cultural phenomena in the environment which results in the failure of the individual to communicate and respond in the most appropriate manner within the context of society. Language acquisition and language use are commonly used in assessing this concept. *Year introduced: 1968* Cultural Characteristics: Those aspects or characteristics which identify a culture. *Year introduced: 1991(1975)* Cross-Cultural Comparison: Comparison of various psychological, sociological, or cultural factors in order to assess the similarities or diversities occurring in two or more different cultures or societies. *Year introduced: 1968* Anthropology, Cultural: It is the study of social phenomena which characterize the learned, shared, and transmitted social activities of particular ethnic groups with focus on the causes, consequences, and complexities of human social and cultural variability. *Year introduced: 1968* Ethnopsychology: Comparative PSYCHOLOGY of different ethnic and cultural groups. Acculturation: Process of cultural change in which one group or members of a group assimilate various cultural patterns from another. *Year introduced: 1963* ethnology [Subheading]: Used with diseases for ethnic, cultural, or anthropological aspects, and with geographic headings to indicate the place of origin of a group of people. *Year introduced: 1975* United Nations: An international organization whose members include most of the sovereign nations of the world with headquarters in New York City. The primary objectives of the organization are to maintain peace and security and to achieve

	international cooperation in solving international economic, social, cultural, or humanitarian problems. *Year introduced: 1980*
Economic differences *Search date: Oct. 5, 2014*	No results
Economic 14 results: *Economics, economics [Subheading], Economic Development, Economic Recession, Economic Models, United States Office of Economic Opportunity, Economic Inflation, Economic Competition, Value of Life, European Union, American Recovery and Reinvestment Act, Nursing Economics, Hospital Economics, United Nations* *Search date: Oct. 5, 2014*	Economics: The science of utilization, distribution, and consumption of services and materials.
Economics 9 results: *Economics, economics [Subheading],* ***Behavioral Economics, Pharmaceutical Economics, Health Care Economics and Organizations, Nursing Economics Medical Economics, Hospital Economics****, Dental Economics* *Search date: Oct. 5, 2014*	Behavioral Economics: The combined discipline of psychology and economics that investigates what happens in markets in which some of the agents display human limitations and complications. *Year introduced: 2012* Pharmaceutical Economics: Economic aspects of the fields of pharmacy and pharmacology as they apply to the development and study of medical economics in rational drug therapy and the impact of pharmaceuticals on the cost of medical care. Pharmaceutical economics also includes the economic considerations of the pharmaceutical care delivery system and in drug prescribing, particularly of cost-benefit values. (From J Res Pharm Econ 1989;1(1); PharmacoEcon 1992;1(1)) *Year introduced: 1994* Health Care Economics and Organizations: The economic aspects of health care, its planning, and delivery. It includes government agencies and organizations in the private sector. *Year introduced: 1998* Nursing Economics: Economic aspects of the nursing profession. *Year introduced: 1966* Medical Economics: Economic aspects of the field of medicine, the medical

	profession, and health care. It includes the economic and financial impact of disease in general on the patient, the physician, society, or government. Hospital Economics: Economic aspects related to the management and operation of a hospital.
Social differences 3 results *Search date: Oct. 5, 2014*	Anthropology, Medical: Field of social science that is concerned with differences between human groups as related to health status and beliefs. *Year introduced: 2012* Interdisciplinary Communication: Communication, in the sense of cross-fertilization of ideas, involving two or more academic disciplines (such as the disciplines that comprise the cross-disciplinary field of bioethics, including the health and biological sciences, the humanities, and the social sciences and law). Also includes problems in communication stemming from differences in patterns of language usage in different academic or medical disciplines. *Year introduced: 2003* Sickness Impact Profile: A quality-of-life scale developed in the United States in 1972 as a measure of health status or dysfunction generated by a disease. It is a behaviorally based questionnaire for patients and addresses activities such as sleep and rest, mobility, recreation, home management, emotional behavior, social interaction, and the like. It measures the patient's perceived health status and is sensitive enough to detect changes or differences in health status occurring over time or between groups. (From Medical Care, vol.xix, no.8, August 1981, p.787-805) *Year introduced: 1995*
Trust *Search date: Oct. 5, 2014*	Trust: Confidence in or reliance on a person or thing. *Year introduced: 2003*

Appendix F: Electronic Bibliographic Database

	HEALTH SERVICE UTILIZATION MODEL				
	Key word/mesh terms				
Ref #	***Health Service Accessibility, Community Health Service***				
	Search / MeSH Term	**Database**	**Date of search**	**# Results**	**Search syntax**
1	Health Service Utilization Model	PubMed	10/23/14	8371	("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields] OR ("health"[All Fields] AND "service"[All Fields]) OR "health service"[All Fields]) AND ("utilization"[Subheading] OR "utilization"[All Fields]) AND model[All Fields]
2	Health Service Utilization Model (limit by last 5 years and humans)	PubMed	10/23/14	2293	(("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields] OR ("health"[All Fields] AND "service"[All Fields]) OR "health service"[All Fields]) AND ("utilization"[Subheading] OR "utilization"[All Fields]) AND model[All Fields]) AND ("2009/10/25"[PDat] : "2014/10/23"[PDat] AND "humans"[MeSH Terms])
3	Health Service Utilization Model AND **Transients AND Migrants** (limit by last 5 years and humans)	PubMed	10/23/14	5 Saved in Zotero	(("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields] OR ("health"[All Fields] AND "service"[All Fields]) OR "health service"[All Fields]) AND ("utilization"[Subheading] OR "utilization"[All Fields]) AND model[All Fields]) AND ("transients and migrants"[MeSH Terms] OR ("transients"[All Fields] AND "migrants"[All Fields]) OR "transients and migrants"[All

					Fields] OR "transients"[All Fields]) AND ("transients and migrants"[MeSH Terms] OR ("transients"[All Fields] AND "migrants"[All Fields]) OR "transients and migrants"[All Fields] OR "migrants"[All Fields]) AND ("2009/10/25"[PDat] : "2014/10/23"[PDat] AND "humans"[MeSH Terms])
4	Health Service Utilization Model AND **border** (limit by last 5 years and humans)	PubMed	10/23/14	6 Saved in Zotero	(("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields] OR ("health"[All Fields] AND "service"[All Fields]) OR "health service"[All Fields]) AND ("utilization"[Subheading] OR "utilization"[All Fields]) AND model[All Fields]) AND border[All Fields] AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
5	Health Service Utilization Model AND **HIV** (limit by last 5 years and humans)	PubMed	10/23/14	135	(("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields] OR ("health"[All Fields] AND "service"[All Fields]) OR "health service"[All Fields]) AND ("utilization"[Subheading] OR "utilization"[All Fields]) AND model[All Fields]) AND ("hiv"[MeSH Terms] OR "hiv"[All Fields]) AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
6	Health Service Accessibility	PubMed	10/24/14	55225	("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields] OR ("health"[All Fields] AND "service"[All Fields]) OR "health service"[All Fields]) AND Accessibility[All Fields]
7	Health Service Accessibility (limit by last 5 years and humans)	PubMed	10/24/14	16022	(("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields] OR ("health"[All Fields] AND "service"[All Fields]) OR "health service"[All Fields]) AND Accessibility[All

					Fields]) AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
8	Health Service Accessibility AND **Model** (limit by last 5 years and humans)	PubMed	10/24/14	1334	(("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields] OR ("health"[All Fields] AND "service"[All Fields]) OR "health service"[All Fields]) AND Accessibility[All Fields]) AND model[All Fields] AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
9	Health Service Accessibility AND **border** (limit by last 5 years and humans)	PubMed	10/26/14	91	(("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields] OR ("health"[All Fields] AND "service"[All Fields]) OR "health service"[All Fields]) AND accessibility[All Fields]) AND border[All Fields] AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
10	Health Service Accessibility AND **Transients AND Migrants** (limit by last 5 years and humans)	PubMed	10/26/14	210	(("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields] OR ("health"[All Fields] AND "service"[All Fields]) OR "health service"[All Fields]) AND accessibility[All Fields]) AND ("transients and migrants"[MeSH Terms] OR ("transients"[All Fields] AND "migrants"[All Fields]) OR "transients and migrants"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
11	Health Service Accessibility AND **Transients AND Migrants** AND **HIV** (limit by last 5 years and humans)	PubMed	10/26/14	30	(("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields] OR ("health"[All Fields] AND "service"[All Fields]) OR "health service"[All Fields]) AND accessibility[All Fields]) AND ("transients and migrants"[MeSH Terms] OR ("transients"[All Fields] AND "migrants"[All Fields]) OR "transients and migrants"[All Fields]) AND ("hiv"[MeSH Terms] OR "hiv"[All Fields]) AND

					("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
12	Health Service Accessibility AND **Model** AND **border** (limit by last 5 years and humans)	PubMed	10/24/14	8	(("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields] OR ("health"[All Fields] AND "service"[All Fields]) OR "health service"[All Fields]) AND Accessibility[All Fields]) AND model[All Fields] AND border[All Fields] AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
13	Health Service Accessibility AND **Model** AND **border** AND **HIV** (limit by last 5 years and humans)	PubMed	10/24/14	1	*STI and HIV prevention in female sex workers at border communities in Central America*
14	Health Service Accessibility AND **border** AND **HIV** (limit by last 5 years and humans)	PubMed	10/24/14	4	(("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields] OR ("health"[All Fields] AND "service"[All Fields]) OR "health service"[All Fields]) AND Accessibility[All Fields]) AND border[All Fields] AND ("hiv"[MeSH Terms] OR "hiv"[All Fields]) AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
15	Community Health Service (limit by last 5 years and humans)	PubMed	10/24/14	95851	("community health services"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "services"[All Fields]) OR "community health services"[All Fields] OR ("community"[All Fields] AND "health"[All Fields] AND "service"[All Fields]) OR "community health service"[All Fields]) AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
16	Community Health Service AND **Model** (limit by last 5 years and humans)	PubMed	10/24/14	7818	("community health services"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "services"[All Fields]) OR "community health services"[All Fields] OR ("community"[All Fields] AND

					"health"[All Fields] AND "service"[All Fields]) OR "community health service"[All Fields]) AND model[All Fields] AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
17	Community Health Service AND **Transients and Migrants** (limit by last 5 years and humans)	PubMed	10/26/14	219	("community health services"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "services"[All Fields]) OR "community health services"[All Fields] OR ("community"[All Fields] AND "health"[All Fields] AND "service"[All Fields]) OR "community health service"[All Fields]) AND ("transients and migrants"[MeSH Terms] OR ("transients"[All Fields] AND "migrants"[All Fields]) OR "transients and migrants"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
18	Community Health Service AND **border** (limit by last 5 years and humans)	PubMed	10/26/14	140	("community health services"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "services"[All Fields]) OR "community health services"[All Fields] OR ("community"[All Fields] AND "health"[All Fields] AND "service"[All Fields]) OR "community health service"[All Fields]) AND border[All Fields] AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
19	Community Health Service AND **border** AND **community networks** (limit by last 5 years and humans)	PubMed	10/26/14	9	("community health services"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "services"[All Fields]) OR "community health services"[All Fields] OR ("community"[All Fields] AND "health"[All Fields] AND "service"[All Fields]) OR "community health service"[All Fields]) AND border[All Fields] AND ("community networks"[MeSH Terms] OR ("community"[All Fields] AND "networks"[All Fields]) OR "community networks"[All Fields]) AND

					("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
20	Community Health Service AND **border** AND **cooperative behavior** (limit by last 5 years and humans)	PubMed	10/26/14	1	*Cross-border health care in Europe: will centers of reference for pediatric diabetes serve as a model?*
21	Community Health Service AND **border** AND **population dynamics** (limit by last 5 years and humans)	PubMed	10/26/14	7	("community health services"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "services"[All Fields]) OR "community health services"[All Fields] OR ("community"[All Fields] AND "health"[All Fields] AND "service"[All Fields]) OR "community health service"[All Fields]) AND border[All Fields] AND ("population dynamics"[MeSH Terms] OR ("population"[All Fields] AND "dynamics"[All Fields]) OR "population dynamics"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
22	Community Health Service AND **Model** AND **border** (limit by last 5 years and humans)	PubMed	10/24/14	13	("community health services"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "services"[All Fields]) OR "community health services"[All Fields] OR ("community"[All Fields] AND "health"[All Fields] AND "service"[All Fields]) OR "community health service"[All Fields]) AND model[All Fields] AND border[All Fields] AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
23	Community Health Service AND **Model** AND **border** AND **HIV** (limit by last 5 years and humans)	PubMed	10/24/14	1	*Controlling HIV epidemics among injection drug users: eight years of Cross-Border HIV prevention interventions in Vietnam and China.*
	AVAILABILITY				
	Key word/mesh terms				
	Health disparities, Health Manpower, Community				

	Health Workers				
	Search / MeSH Term	**Database**	**Date of search**	**# Results**	**Search syntax**
24	Availability (limit by last 5 years and humans)	PubMed	10/24/14	24308	Availability[All Fields] AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
25	Availability AND **Health Services** (limit by last 5 years and humans)	PubMed	10/24/14	5272	Availability[All Fields] AND ("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields]) AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
26	Availability AND **Health Services** AND **HIV** (limit by last 5 years and humans)	PubMed	10/24/14	357	Availability[All Fields] AND ("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields]) AND ("hiv"[MeSH Terms] OR "hiv"[All Fields]) AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
27	Availability AND **Health Services** AND **HIV** AND **border** (limit by last 5 years and humans)	PubMed	10/24/14	1	*Delays in the diagnosis of tuberculosis in a town at the triple border of Brazil, Paraguay, and Argentina*
28	Availability AND **Health Services** AND **HIV** AND **transients and migrants** (limit by last 5 years and humans)	PubMed	10/24/14	2	Availability[All Fields] AND ("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields]) AND ("hiv"[MeSH Terms] OR "hiv"[All Fields]) AND ("transients and migrants"[MeSH Terms] OR ("transients"[All Fields] AND "migrants"[All Fields]) OR "transients and migrants"[All Fields]) AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
29	Availability AND **Health Services** AND **population dynamics** (limit by last 5 years and humans)	PubMed	10/26/14	37	Availability[All Fields] AND ("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields]) AND

					("population dynamics"[MeSH Terms] OR ("population"[All Fields] AND "dynamics"[All Fields]) OR "population dynamics"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
30	Availability AND **Health Services** AND **population dynamics** AND **HIV** (limit by last 5 years and humans)	PubMed	10/26/14	1	*HIV-1 diversity and drug resistance mutations among people seeking HIV diagnosis in voluntary counseling and testing sites in Rio de Janeiro, Brazil*
31	Availability AND **Health Services** AND **Community Networks** (limit by last 5 years and humans)	PubMed	10/26/14	61	Availability[All Fields] AND ("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields]) AND ("community networks"[MeSH Terms] OR ("community"[All Fields] AND "networks"[All Fields]) OR "community networks"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
32	Availability AND **Health Services** AND **Community Networks** AND **HIV** (limit by last 5 years and humans)	PubMed	10/26/14	11	Availability[All Fields] AND ("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields]) AND ("community networks"[MeSH Terms] OR ("community"[All Fields] AND "networks"[All Fields]) OR "community networks"[All Fields]) AND ("hiv"[MeSH Terms] OR "hiv"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
33	Availability AND **Health Services** AND **cooperative behavior** (limit by last 5 years and humans)	PubMed	10/26/14	70	Availability[All Fields] AND ("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields]) AND ("cooperative behaviour"[All Fields] OR "cooperative behavior"[MeSH Terms] OR ("cooperative"[All Fields] AND "behavior"[All Fields]) OR "cooperative behavior"[All Fields]) AND ("2009/10/28"[PDat] :

					"2014/10/26"[PDat] AND "humans"[MeSH Terms])
34	Availability AND **Health Services** AND **cooperative behavior** AND **HIV** (limit by last 5 years and humans)	PubMed	10/26/14	5	Availability[All Fields] AND ("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields]) AND ("cooperative behaviour"[All Fields] OR "cooperative behavior"[MeSH Terms] OR ("cooperative"[All Fields] AND "behavior"[All Fields]) OR "cooperative behavior"[All Fields]) AND ("hiv"[MeSH Terms] OR "hiv"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
35	Healthcare disparities (limit by last 5 years and humans)	PubMed	10/24/14	6063	("healthcare disparities"[MeSH Terms] OR ("healthcare"[All Fields] AND "disparities"[All Fields]) OR "healthcare disparities"[All Fields]) AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
36	Healthcare disparities AND Availability (limit by last 5 years and humans)	PubMed	10/24/14	173	("healthcare disparities"[MeSH Terms] OR ("healthcare"[All Fields] AND "disparities"[All Fields]) OR "healthcare disparities"[All Fields]) AND availability[All Fields] AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
37	**Healthcare disparities** AND Availability AND **health services** (limit by last 5 years and humans)	PubMed	10/24/14	148	("healthcare disparities"[MeSH Terms] OR ("healthcare"[All Fields] AND "disparities"[All Fields]) OR "healthcare disparities"[All Fields]) AND availability[All Fields] AND ("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields]) AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
38	**Healthcare disparities** AND Availability AND **border** (limit by last 5 years and humans)	PubMed	10/26/14	0	("healthcare disparities"[MeSH Terms] OR ("healthcare"[All Fields] AND "disparities"[All Fields]) OR "healthcare disparities"[All Fields]) AND Availability[All Fields] AND border[All Fields] AND ("2009/10/28"[PDat]

					: "2014/10/26"[PDat] AND "humans"[MeSH Terms])
39	**Healthcare disparities** AND Availability AND **health services** AND **border** (limit by last 5 years and humans)	PubMed	10/26/14	0	("healthcare disparities"[MeSH Terms] OR ("healthcare"[All Fields] AND "disparities"[All Fields]) OR "healthcare disparities"[All Fields]) AND Availability[All Fields] AND ("health services"[MeSH Terms] OR ("health"[All Fields] AND "services"[All Fields]) OR "health services"[All Fields]) AND border[All Fields] AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
40	**Healthcare disparities** AND Availability AND **health services** AND **transients and migrants** (limit by last 5 years and humans)	PubMed	10/26/14	0	("healthcare disparities"[MeSH Terms] OR ("healthcare"[All Fields] AND "disparities"[All Fields]) OR "healthcare disparities"[All Fields]) AND Availability[All Fields] AND ("transients and migrants"[MeSH Terms] OR ("transients"[All Fields] AND "migrants"[All Fields]) OR "transients and migrants"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
41	**Healthcare disparities** AND Availability AND **health services** AND **population dynamics** (limit by last 5 years and humans)	PubMed	10/26/14	1	*Disparities in public use data availability for race, ethnic, and immigrant groups: national surveys for healthcare disparities research*
42	**Healthcare disparities** AND Availability AND **health services** AND **community networks** (limit by last 5 years and humans)	PubMed	10/26/14	2	("healthcare disparities"[MeSH Terms] OR ("healthcare"[All Fields] AND "disparities"[All Fields]) OR "healthcare disparities"[All Fields]) AND Availability[All Fields] AND ("community networks"[MeSH Terms] OR ("community"[All Fields] AND "networks"[All Fields]) OR "community networks"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
43	**Healthcare disparities** AND Availability AND **health services** AND	PubMed	10/26/14	2	("healthcare disparities"[MeSH Terms] OR ("healthcare"[All Fields] AND "disparities"[All Fields]) OR

	cooperative behavior (limit by last 5 years and humans)				"healthcare disparities"[All Fields]) AND Availability[All Fields] AND ("cooperative behaviour"[All Fields] OR "cooperative behavior"[MeSH Terms] OR ("cooperative"[All Fields] AND "behavior"[All Fields]) OR "cooperative behavior"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
44	Health Manpower (limit by last 5 years and humans)	PubMed	10/24/14	6718	("health manpower"[MeSH Terms] OR ("health"[All Fields] AND "manpower"[All Fields]) OR "health manpower"[All Fields]) AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
45	Health Manpower AND Availability (limit by last 5 years and humans)	PubMed	10/24/14	251	("health manpower"[MeSH Terms] OR ("health"[All Fields] AND "manpower"[All Fields]) OR "health manpower"[All Fields]) AND availability[All Fields] AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
46	**Health Manpower** AND Availability AND **HIV** (limit by last 5 years and humans)	PubMed	10/26/14	9	("health manpower"[MeSH Terms] OR ("health"[All Fields] AND "manpower"[All Fields]) OR "health manpower"[All Fields]) AND Availability[All Fields] AND ("hiv"[MeSH Terms] OR "hiv"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
47	**Health Manpower** AND Availability AND **border** (limit by last 5 years and humans)	PubMed	10/26/14	1	*Mapping oncology services in regional and rural Australia*
48	**Health Manpower** AND Availability AND **transients and migrants** (limit by last 5 years and humans)	PubMed	10/26/14	1	*Health of mobile pastoralists in the Sahel - assessment of 15 years of research and development*
49	**Health Manpower** AND Availability AND **emigration and immigration** (limit by last 5 years and humans)	PubMed	10/26/14	2	("health manpower"[MeSH Terms] OR ("health"[All Fields] AND "manpower"[All Fields]) OR "health manpower"[All Fields]) AND Availability[All Fields] AND

					("emigration and immigration"[MeSH Terms] OR ("emigration"[All Fields] AND "immigration"[All Fields]) OR "emigration and immigration"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
50	**Health Manpower** AND Availability AND **cooperative behavior** (limit by last 5 years and humans)	PubMed	10/26/14	5	("health manpower"[MeSH Terms] OR ("health"[All Fields] AND "manpower"[All Fields]) OR "health manpower"[All Fields]) AND Availability[All Fields] AND ("cooperative behaviour"[All Fields] OR "cooperative behavior"[MeSH Terms] OR ("cooperative"[All Fields] AND "behavior"[All Fields]) OR "cooperative behavior"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
51	**Health Manpower** AND Availability AND **community networks** (limit by last 5 years and humans)	PubMed	10/26/14	2	("health manpower"[MeSH Terms] OR ("health"[All Fields] AND "manpower"[All Fields]) OR "health manpower"[All Fields]) AND Availability[All Fields] AND ("community networks"[MeSH Terms] OR ("community"[All Fields] AND "networks"[All Fields]) OR "community networks"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
52	**Health Manpower** AND Availability AND **population dynamics** (limit by last 5 years and humans)	PubMed	10/26/14	2	("health manpower"[MeSH Terms] OR ("health"[All Fields] AND "manpower"[All Fields]) OR "health manpower"[All Fields]) AND Availability[All Fields] AND ("population dynamics"[MeSH Terms] OR ("population"[All Fields] AND "dynamics"[All Fields]) OR "population dynamics"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
53	**Health Manpower** AND Availability AND **parish nursing**	PubMed	10/26/14	0	

	(limit by last 5 years and humans)				
54	**Health Manpower** AND Availability AND **health services for transgendered persons** (limit by last 5 years and humans)	PubMed	10/26/14	0	
55	**Health Manpower** AND Availability AND **voluntary health agency** (limit by last 5 years and humans)	PubMed	10/26/14	1	*Caregiving in a patient's place of residence: turnover of direct care workers in home care and hospice agencies*.
56	**Health Manpower** AND Availability AND **public-private sector partnerships** (limit by last 5 years and humans)	PubMed	10/26/14	1	*Private sector approaches to workforce enhancement.*
57	**Health Manpower** AND Availability AND **community psychiatry** (limit by last 5 years and humans)	PubMed	10/26/14	2	("health manpower"[MeSH Terms] OR ("health"[All Fields] AND "manpower"[All Fields]) OR "health manpower"[All Fields]) AND Availability[All Fields] AND ("community psychiatry"[MeSH Terms] OR ("community"[All Fields] AND "psychiatry"[All Fields]) OR "community psychiatry"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
58	**Community Health Workers** (limit by last 5 years and humans)	PubMed	10/24/14	3134	("community health workers"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "workers"[All Fields]) OR "community health workers"[All Fields]) AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
59	**Community Health Workers** AND Availability (limit by last 5 years and humans)	PubMed	10/24/14	114	("community health workers"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "workers"[All Fields]) OR "community health workers"[All Fields]) AND availability[All Fields] AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])

60	**Community Health Workers** AND Availability AND **Voluntary health agency** (limitations removed)	PubMed	10/26/14	2	("community health workers"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "workers"[All Fields]) OR "community health workers"[All Fields]) AND Availability[All Fields] AND ("voluntary health agencies"[MeSH Terms] OR ("voluntary"[All Fields] AND "health"[All Fields] AND "agencies"[All Fields]) OR "voluntary health agencies"[All Fields] OR ("voluntary"[All Fields] AND "health"[All Fields] AND "agency"[All Fields]) OR "voluntary health agency"[All Fields])
61	**Community Health Workers** AND Availability AND **private-public sector partnerships** (limit by last 5 years and humans)	PubMed	10/26/14	0; even with limitation removed	
62	**Community Health Workers** AND Availability AND **parish nursing** (limit by last 5 years and humans)	PubMed	10/26/14	0; even with limitation removed	
63	**Community Health Workers** AND Availability AND **cooperative behavior** (limit by last 5 years and humans)	PubMed	10/26/14	1	*Health system barriers to implementation of collaborative TB and HIV activities including prevention of mother to child transmission in South Africa*
64	**Community Health Workers** AND Availability AND **community networks** (limit by last 5 years and humans)	PubMed	10/26/14	3	("community health workers"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "workers"[All Fields]) OR "community health workers"[All Fields]) AND Availability[All Fields] AND ("community networks"[MeSH Terms] OR ("community"[All Fields] AND "networks"[All Fields]) OR "community networks"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
65	**Community Health Workers** AND	PubMed	10/26/14	0; even	

	Availability AND **Health Services for Transgendered Persons** (limit by last 5 years and humans)			with limitation removed	
66	**Community Health Workers** AND Availability AND **population dynamics** (limitations removed)[5]	PubMed	10/26/14	35	("community health workers"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "workers"[All Fields]) OR "community health workers"[All Fields]) AND Availability[All Fields] AND ("population dynamics"[MeSH Terms] OR ("population"[All Fields] AND "dynamics"[All Fields]) OR "population dynamics"[All Fields])
67	**Community Health Workers** AND Availability AND **border** (limit by last 5 years and humans)	PubMed	10/26/14	3	("community health workers"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "workers"[All Fields]) OR "community health workers"[All Fields]) AND Availability[All Fields] AND border[All Fields] AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
68	**Community Health Workers** AND Availability AND **transients and migrants** (limitations removed)	PubMed	10/26/14	6	("community health workers"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "workers"[All Fields]) OR "community health workers"[All Fields]) AND Availability[All Fields] AND ("transients and migrants"[MeSH Terms] OR ("transients"[All Fields] AND "migrants"[All Fields]) OR "transients and migrants"[All Fields])
69	**Community Health Workers** AND Availability AND **emigration and immigration** (limitations removed)	PubMed	10/26/14	4	("community health workers"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "workers"[All Fields]) OR "community health workers"[All Fields]) AND Availability[All Fields] AND ("emigration and immigration"[MeSH Terms] OR ("emigration"[All Fields] AND "immigration"[All Fields])

[5] Limitations (i.e., “past 5 years” and “human”) were removed when PubMed search indicated 0 references with limitations, but suggested reviewing the X publications fitting the search syntax with limitations (i.e., “past 5 years” and “human”) removed.

					OR "emigration and immigration"[All Fields])
	ACCESSIBILITY				
	Key word/mesh terms				
	Health Service Accessibility, Community Health Planning, Health Care Quality Access and Evaluation, Medically Underserved Area				
	Search / MeSH Term	**Database**	**Date of search**	**# Results**	**Search syntax**
70	**Community Health Planning** (limit by last 5 years and humans)	PubMed	10/24/14	3600	("community health planning"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "planning"[All Fields]) OR "community health planning"[All Fields]) AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
71	**Community Health Planning** AND Accessibility (limit by last 5 years and humans)	PubMed	10/24/14	112	("community health planning"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "planning"[All Fields]) OR "community health planning"[All Fields]) AND Availability[All Fields] AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
72	**Community Health Planning** AND Accessibility AND **emigration and immigration** (limitations removed)	PubMed	10/26/14	11	("community health planning"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "planning"[All Fields]) OR "community health planning"[All Fields]) AND Accessibility[All Fields] AND ("emigration and immigration"[MeSH Terms] OR ("emigration"[All Fields] AND "immigration"[All Fields]) OR "emigration and immigration"[All Fields]
73	**Community Health Planning** AND Accessibility AND **border** (limitations removed)	PubMed	10/26/14	5	("community health planning"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "planning"[All Fields]) OR "community health planning"[All Fields]) AND Accessibility[All Fields] AND border[All Fields]
74	**Community Health Planning** AND Accessibility AND **transients and**	PubMed	10/26/14	8	("community health planning"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND

	migrants (limitations removed)				"planning"[All Fields]) OR "community health planning"[All Fields]) AND Accessibility[All Fields] AND ("transients and migrants"[MeSH Terms] OR ("transients"[All Fields] AND "migrants"[All Fields]) OR "transients and migrants"[All Fields])
75	**Community Health Planning** AND Accessibility AND **population dynamics** (limit by last 10 years and humans)	PubMed	10/26/14	15	("community health planning"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "planning"[All Fields]) OR "community health planning"[All Fields]) AND Accessibility[All Fields] AND ("population dynamics"[MeSH Terms] OR ("population"[All Fields] AND "dynamics"[All Fields]) OR "population dynamics"[All Fields]) AND ("2004/10/29"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
76	**Community Health Planning** AND Accessibility AND **HIV** (limit by last 5 years and humans)	PubMed	10/26/14	22	("community health planning"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "planning"[All Fields]) OR "community health planning"[All Fields]) AND Accessibility[All Fields] AND ("hiv"[MeSH Terms] OR "hiv"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
77	**Community Health Planning** AND Accessibility AND **cooperative behavior** (limit by last 5 years and humans)	PubMed	10/26/14	22	("community health planning"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "planning"[All Fields]) OR "community health planning"[All Fields]) AND Accessibility[All Fields] AND ("cooperative behaviour"[All Fields] OR "cooperative behavior"[MeSH Terms] OR ("cooperative"[All Fields] AND "behavior"[All Fields]) OR "cooperative behavior"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
78	**Community Health Planning** AND	PubMed	10/26/14	21	("community health planning"[MeSH Terms] OR

	Accessibility AND **community networks** (limit by last 5 years and humans)				("community"[All Fields] AND "health"[All Fields] AND "planning"[All Fields]) OR "community health planning"[All Fields]) AND Accessibility[All Fields] AND ("community networks"[MeSH Terms] OR ("community"[All Fields] AND "networks"[All Fields]) OR "community networks"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
79	**Community Health Planning** AND Accessibility AND **communication barriers** (limit by last 5 years and humans)	PubMed	10/26/14	12	("community health planning"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "planning"[All Fields]) OR "community health planning"[All Fields]) AND Accessibility[All Fields] AND ("communication barriers"[MeSH Terms] OR ("communication"[All Fields] AND "barriers"[All Fields]) OR "communication barriers"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
80	**Community Health Planning** AND Accessibility AND **social isolation** (limit by last 5 years and humans)	PubMed	10/26/14	1	*Microcredit, family planning programs, and contraceptive behavior: evidence from a field experiment in Ethiopia*
81	**Community Health Planning** AND Accessibility AND **poverty areas** (limit by last 5 years and humans)	PubMed	10/26/14	10	("community health planning"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "planning"[All Fields]) OR "community health planning"[All Fields]) AND Accessibility[All Fields] AND ("poverty areas"[MeSH Terms] OR ("poverty"[All Fields] AND "areas"[All Fields]) OR "poverty areas"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
82	**Community Health Planning** AND Accessibility AND **culture** (limit by last 5 years and humans)	PubMed	10/26/14	38	("community health planning"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "planning"[All Fields]) OR "community health

					planning"[All Fields]) AND Accessibility[All Fields] AND ("ethnology"[Subheading] OR "ethnology"[All Fields] OR "culture"[All Fields] OR "culture"[MeSH Terms]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
83	**Community Health Planning** AND Accessibility AND **cultural competency** (limit by last 5 years and humans)	PubMed	10/26/14	6	("community health planning"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "planning"[All Fields]) OR "community health planning"[All Fields]) AND Accessibility[All Fields] AND ("cultural competency"[MeSH Terms] OR ("cultural"[All Fields] AND "competency"[All Fields]) OR "cultural competency"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
84	**Community Health Planning** AND Accessibility AND **economics** (limit by last 5 years and humans)	PubMed	10/26/14	66	("community health planning"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "planning"[All Fields]) OR "community health planning"[All Fields]) AND Accessibility[All Fields] AND ("economics"[Subheading] OR "economics"[All Fields] OR "economics"[MeSH Terms]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
85	**Community Health Planning** AND Accessibility AND **behavioral economics** (limit by last 5 years and humans)	PubMed	10/26/14	2	("community health planning"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "planning"[All Fields]) OR "community health planning"[All Fields]) AND Accessibility[All Fields] AND ("economics, behavioral"[MeSH Terms] OR ("economics"[All Fields] AND "behavioral"[All Fields]) OR "behavioral economics"[All Fields] OR ("behavioral"[All Fields] AND "economics"[All Fields])) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])

86	**Community Health Planning** AND Accessibility AND **behavioral economics** (no limitations)	PubMed	10/26/14	7	("community health planning"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "planning"[All Fields]) OR "community health planning"[All Fields]) AND Accessibility[All Fields] AND ("economics, behavioral"[MeSH Terms] OR ("economics"[All Fields] AND "behavioral"[All Fields]) OR "behavioral economics"[All Fields] OR ("behavioral"[All Fields] AND "economics"[All Fields]))
87	**Community Health Planning** AND Accessibility AND **Health Care Economics and Organizations** (limit by last 5 years and humans)	PubMed	10/26/14	201	("community health planning"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "planning"[All Fields]) OR "community health planning"[All Fields]) AND Accessibility[All Fields] AND ("health care economics and organizations"[MeSH Terms] OR ("health"[All Fields] AND "care"[All Fields] AND "economics"[All Fields] AND "organizations"[All Fields]) OR "health care economics and organizations"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
88	**Health Care Economics and Organizations** AND accessibility AND **border** (limit by last 5 years and humans)	PubMed	10/26/14	58	("health care economics and organizations"[MeSH Terms] OR ("health"[All Fields] AND "care"[All Fields] AND "economics"[All Fields] AND "organizations"[All Fields]) OR "health care economics and organizations"[All Fields]) AND accessibility[All Fields] AND border[All Fields] AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
89	**Health Care Economics and Organizations** AND accessibility AND **border** AND **HIV** (limit by last 5 years and humans)	PubMed	10/26/14	2	("health care economics and organizations"[MeSH Terms] OR ("health"[All Fields] AND "care"[All Fields] AND "economics"[All Fields] AND "organizations"[All Fields]) OR "health care economics and organizations"[All Fields]) AND accessibility[All Fields] AND border[All Fields] AND ("hiv"[MeSH Terms] OR

					"hiv"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
90	Health Care Quality Access and Evaluation (limit by last 5 years and humans)	PubMed	10/24/14	6091	(("quality of health care"[MeSH Terms] OR ("quality"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "quality of health care"[All Fields] OR ("health"[All Fields] AND "care"[All Fields] AND "quality"[All Fields]) OR "health care quality"[All Fields]) AND access[All Fields] AND ("evaluation studies"[Publication Type] OR "evaluation studies as topic"[MeSH Terms] OR "evaluation"[All Fields])) AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
91	**Health Care Quality Access and Evaluation** AND Accessibility (limit by last 5 years and humans)	PubMed	10/24/14	769	(("quality of health care"[MeSH Terms] OR ("quality"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "quality of health care"[All Fields] OR ("health"[All Fields] AND "care"[All Fields] AND "quality"[All Fields]) OR "health care quality"[All Fields]) AND access[All Fields] AND ("evaluation studies"[Publication Type] OR "evaluation studies as topic"[MeSH Terms] OR "evaluation"[All Fields])) AND accessibility[All Fields] AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
92	Health Care Quality Access and Evaluation AND Accessibility AND **HIV** (limit by last 5 years and humans)	PubMed	10/26/14	83	(("quality of health care"[MeSH Terms] OR ("quality"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "quality of health care"[All Fields] OR ("health"[All Fields] AND "care"[All Fields] AND "quality"[All Fields]) OR "health care quality"[All Fields]) AND Access[All Fields] AND ("evaluation studies"[Publication Type] OR "evaluation studies as topic"[MeSH Terms] OR "evaluation"[All Fields])) AND Accessibility[All Fields] AND ("hiv"[MeSH Terms] OR "hiv"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND

					"humans"[MeSH Terms])
93	Health Care Quality Access and Evaluation AND Accessibility AND **HIV** AND **border** (limit by last 5 years and humans)	PubMed	10/26/14	0	
94	**Health Care Quality Access and Evaluation** AND Accessibility AND **border** (limit by last 5 years and humans)	PubMed	10/26/14	8	(("quality of health care"[MeSH Terms] OR ("quality"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "quality of health care"[All Fields] OR ("health"[All Fields] AND "care"[All Fields] AND "quality"[All Fields]) OR "health care quality"[All Fields]) AND Access[All Fields] AND ("evaluation studies"[Publication Type] OR "evaluation studies as topic"[MeSH Terms] OR "evaluation"[All Fields])) AND Accessibility[All Fields] AND border[All Fields]
95	Accessibility AND **border**	PubMed	10/26/14	278	Accessibility[All Fields] AND border[All Fields]
96	Accessibility AND **border** (limit by last 5 years and humans)	PubMed	10/26/14	97	Accessibility[All Fields] AND border[All Fields] AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
97	**Medically Underserved Area** (limit by last 5 years and humans)	PubMed	10/24/14	1336	("medically underserved area"[MeSH Terms] OR ("medically"[All Fields] AND "underserved"[All Fields] AND "area"[All Fields]) OR "medically underserved area"[All Fields]) AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
98	Medically Underserved Area AND Accessibility (limit by last 5 years and humans)	PubMed	10/24/14	358	("medically underserved area"[MeSH Terms] OR ("medically"[All Fields] AND "underserved"[All Fields] AND "area"[All Fields]) OR "medically underserved area"[All Fields]) AND accessibility[All Fields] AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
99	Medically Underserved Area AND Accessible	PubMed	10/26/14	23	("medically underserved area"[MeSH Terms] OR ("medically"[All Fields] AND "underserved"[All Fields]

	(limit by last 5 years and humans)				AND "area"[All Fields]) OR "medically underserved area"[All Fields]) AND Accessible[All Fields] AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
100	Medically Underserved Area AND **border** (limit by last 5 years and humans)	PubMed	10/26/14	6	("medically underserved area"[MeSH Terms] OR ("medically"[All Fields] AND "underserved"[All Fields] AND "area"[All Fields]) OR "medically underserved area"[All Fields]) AND border[All Fields] AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
101	Medically Underserved Area AND **transients and migrants** (limit by last 5 years and humans)	PubMed	10/26/14	6	("medically underserved area"[MeSH Terms] OR ("medically"[All Fields] AND "underserved"[All Fields] AND "area"[All Fields]) OR "medically underserved area"[All Fields]) AND ("transients and migrants"[MeSH Terms] OR ("transients"[All Fields] AND "migrants"[All Fields]) OR "transients and migrants"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
102	Medically Underserved Area AND **emigration and immigration** (limit by last 5 years and humans)	PubMed	10/26/14	14	("medically underserved area"[MeSH Terms] OR ("medically"[All Fields] AND "underserved"[All Fields] AND "area"[All Fields]) OR "medically underserved area"[All Fields]) AND ("emigration and immigration"[MeSH Terms] OR ("emigration"[All Fields] AND "immigration"[All Fields]) OR "emigration and immigration"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
103	Medically Underserved Area AND **HIV** (limit by last 5 years and humans)	PubMed	10/26/14	36	("medically underserved area"[MeSH Terms] OR ("medically"[All Fields] AND "underserved"[All Fields] AND "area"[All Fields]) OR "medically underserved area"[All Fields]) AND ("hiv"[MeSH Terms] OR "hiv"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat]

					AND "humans"[MeSH Terms])
104	Medically Underserved Area AND **cooperative behavior** (limit by last 5 years and humans)	PubMed	10/26/14	51	("medically underserved area"[MeSH Terms] OR ("medically"[All Fields] AND "underserved"[All Fields] AND "area"[All Fields]) OR "medically underserved area"[All Fields]) AND ("cooperative behaviour"[All Fields] OR "cooperative behavior"[MeSH Terms] OR ("cooperative"[All Fields] AND "behavior"[All Fields]) OR "cooperative behavior"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
105	Medically Underserved Area AND **community networks** (limit by last 5 years and humans)	PubMed	10/26/14	36	("medically underserved area"[MeSH Terms] OR ("medically"[All Fields] AND "underserved"[All Fields] AND "area"[All Fields]) OR "medically underserved area"[All Fields]) AND ("community networks"[MeSH Terms] OR ("community"[All Fields] AND "networks"[All Fields]) OR "community networks"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
106	Medically Underserved Area AND **population dynamics** (limit by last 5 years and humans)	PubMed	10/26/14	27	("medically underserved area"[MeSH Terms] OR ("medically"[All Fields] AND "underserved"[All Fields] AND "area"[All Fields]) OR "medically underserved area"[All Fields]) AND ("population dynamics"[MeSH Terms] OR ("population"[All Fields] AND "dynamics"[All Fields]) OR "population dynamics"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
	ACCEPTABILITY				
	Key word/mesh terms				
	Patient Acceptance of Health Care				
	Search / MeSH Term	**Database**	**Date of search**	**# Results**	**Search syntax**

107	**Patient Acceptance of Health Care** (limit by last 5 years and humans)	PubMed	10/24/14	46798	("patient acceptance of health care"[MeSH Terms] OR ("patient"[All Fields] AND "acceptance"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "patient acceptance of health care"[All Fields]) AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
108	**Patient Acceptance of Health Care** AND Acceptability (limit by last 5 years and humans)	PubMed	10/24/14	1467	("patient acceptance of health care"[MeSH Terms] OR ("patient"[All Fields] AND "acceptance"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "patient acceptance of health care"[All Fields]) AND acceptability[All Fields] AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
109	**Patient Acceptance of Health Care** AND Acceptability AND **HIV** (limit by last 5 years and humans)	PubMed	10/26/14	280	("patient acceptance of health care"[MeSH Terms] OR ("patient"[All Fields] AND "acceptance"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "patient acceptance of health care"[All Fields]) AND Acceptability[All Fields] AND ("hiv"[MeSH Terms] OR "hiv"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
110	**Patient Acceptance of Health Care** AND Acceptability AND **HIV** AND **border** (limit by last 5 years and humans)	PubMed	10/26/14	1	*Acceptability of vaginal microbicides among female sex workers and their intimate male partners in two Mexico-US border cities: a mixed methods analysis.*
111	**Patient Acceptance of Health Care** AND Acceptability AND **border** (limit by last 5 years and humans)	PubMed	10/26/14	4	("patient acceptance of health care"[MeSH Terms] OR ("patient"[All Fields] AND "acceptance"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "patient acceptance of health care"[All Fields]) AND Acceptability[All Fields] AND border[All Fields] AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
112	**Patient Acceptance of Health Care**	PubMed	10/26/14	85	("patient acceptance of health care"[MeSH Terms] OR

	AND **border** (limit by last 5 years and humans)				("patient"[All Fields] AND "acceptance"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "patient acceptance of health care"[All Fields]) AND border[All Fields] AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
113	**Patient Acceptance of Health Care** AND **population dynamics** (limit by last 5 years and humans)	PubMed	10/26/14	106	("patient acceptance of health care"[MeSH Terms] OR ("patient"[All Fields] AND "acceptance"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "patient acceptance of health care"[All Fields]) AND ("population dynamics"[MeSH Terms] OR ("population"[All Fields] AND "dynamics"[All Fields]) OR "population dynamics"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
114	**Patient Acceptance of Health Care** AND **patient satisfaction** (limit by last 5 years and humans)	PubMed	10/24/14	20228	("patient acceptance of health care"[MeSH Terms] OR ("patient"[All Fields] AND "acceptance"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "patient acceptance of health care"[All Fields]) AND ("patient satisfaction"[MeSH Terms] OR ("patient"[All Fields] AND "satisfaction"[All Fields]) OR "patient satisfaction"[All Fields]) AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
115	Patient Acceptance of Health Care AND **patient satisfaction** AND **population dynamics**	PubMed	10/26/14	25	("patient acceptance of health care"[MeSH Terms] OR ("patient"[All Fields] AND "acceptance"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "patient acceptance of health care"[All Fields]) AND ("patient satisfaction"[MeSH Terms] OR ("patient"[All Fields] AND "satisfaction"[All Fields]) OR "patient satisfaction"[All Fields]) AND ("population dynamics"[MeSH Terms] OR ("population"[All Fields] AND "dynamics"[All Fields]) OR "population dynamics"[All Fields]) AND

					("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
116	**Patient Acceptance of Health Care** AND **patient satisfaction** AND **HIV** (limit by last 5 years and humans)	PubMed	10/24/14	278	("patient acceptance of health care"[MeSH Terms] OR ("patient"[All Fields] AND "acceptance"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "patient acceptance of health care"[All Fields]) AND ("patient satisfaction"[MeSH Terms] OR ("patient"[All Fields] AND "satisfaction"[All Fields]) OR "patient satisfaction"[All Fields]) AND ("hiv"[MeSH Terms] OR "hiv"[All Fields]) AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
117	**Patient Acceptance of Health Care** AND **patient satisfaction** AND **barriers** (limit by last 5 years and humans)	PubMed	10/26/14	601	("patient acceptance of health care"[MeSH Terms] OR ("patient"[All Fields] AND "acceptance"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "patient acceptance of health care"[All Fields]) AND ("patient satisfaction"[MeSH Terms] OR ("patient"[All Fields] AND "satisfaction"[All Fields]) OR "patient satisfaction"[All Fields]) AND barriers[All Fields] AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
118	**Patient Acceptance of Health Care** AND **patient satisfaction** AND **culture** (limit by last 5 years and humans)	PubMed	10/26/14	858	("patient acceptance of health care"[MeSH Terms] OR ("patient"[All Fields] AND "acceptance"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "patient acceptance of health care"[All Fields]) AND ("patient satisfaction"[MeSH Terms] OR ("patient"[All Fields] AND "satisfaction"[All Fields]) OR "patient satisfaction"[All Fields]) AND ("ethnology"[Subheading] OR "ethnology"[All Fields] OR "culture"[All Fields] OR "culture"[MeSH Terms]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
119	**Patient Acceptance of Health Care**	PubMed	10/26/14	92	("patient acceptance of health care"[MeSH Terms] OR

	AND **patient satisfaction** AND **cultural competency** (limit by last 5 years and humans)				("patient"[All Fields] AND "acceptance"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "patient acceptance of health care"[All Fields]) AND ("patient satisfaction"[MeSH Terms] OR ("patient"[All Fields] AND "satisfaction"[All Fields]) OR "patient satisfaction"[All Fields]) AND ("cultural competency"[MeSH Terms] OR ("cultural"[All Fields] AND "competency"[All Fields]) OR "cultural competency"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
120	**Patient Acceptance of Health Care** AND **patient satisfaction** AND **acculturation** (limit by last 5 years and humans)	PubMed	10/26/14	19	("patient acceptance of health care"[MeSH Terms] OR ("patient"[All Fields] AND "acceptance"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "patient acceptance of health care"[All Fields]) AND ("patient satisfaction"[MeSH Terms] OR ("patient"[All Fields] AND "satisfaction"[All Fields]) OR "patient satisfaction"[All Fields]) AND ("acculturation"[MeSH Terms] OR "acculturation"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
121	**Patient Acceptance of Health Care** AND **patient satisfaction** AND **cultural diversity** (limit by last 5 years and humans)	PubMed	10/26/14	36	("patient acceptance of health care"[MeSH Terms] OR ("patient"[All Fields] AND "acceptance"[All Fields] AND "health"[All Fields] AND "care"[All Fields]) OR "patient acceptance of health care"[All Fields]) AND ("patient satisfaction"[MeSH Terms] OR ("patient"[All Fields] AND "satisfaction"[All Fields]) OR "patient satisfaction"[All Fields]) AND ("cultural diversity"[MeSH Terms] OR ("cultural"[All Fields] AND "diversity"[All Fields]) OR "cultural diversity"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
122	**Patient Acceptance of Health Care** AND **patient satisfaction** AND **medical**	PubMed	10/26/14	7	("patient acceptance of health care"[MeSH Terms] OR ("patient"[All Fields] AND "acceptance"[All Fields] AND

	anthropology (limit by last 5 years and humans)				"health"[All Fields] AND "care"[All Fields]) OR "patient acceptance of health care"[All Fields]) AND ("patient satisfaction"[MeSH Terms] OR ("patient"[All Fields] AND "satisfaction"[All Fields]) OR "patient satisfaction"[All Fields]) AND ("anthropology, medical"[MeSH Terms] OR ("anthropology"[All Fields] AND "medical"[All Fields]) OR "medical anthropology"[All Fields] OR ("medical"[All Fields] AND "anthropology"[All Fields])) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
	ACCOUNTABILITY				
	Key word/mesh terms				
	Social Responsibility, Health Insurance Portability and Accountability Act, Managed Competition				
	Search / MeSH Term	**Database**	**Date of search**	**# Results**	**Search syntax**
123	**Social responsibility** AND accountability (limit by last 5 years and humans)	PubMed	10/24/14	4273	("social responsibility"[MeSH Terms] OR ("social"[All Fields] AND "responsibility"[All Fields]) OR "social responsibility"[All Fields]) AND ("social responsibility"[MeSH Terms] OR ("social"[All Fields] AND "responsibility"[All Fields]) OR "social responsibility"[All Fields] OR "accountability"[All Fields]) AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
124	**Social responsibility** and **HIV services** (limit by last 5 years and humans)	PubMed	10/24/14	31	(("social responsibility"[MeSH Terms] OR ("social"[All Fields] AND "responsibility"[All Fields]) OR "social responsibility"[All Fields]) AND ("hiv"[MeSH Terms] OR "hiv"[All Fields]) AND services[All Fields]) AND ("2009/10/26"[PDat] : "2014/10/24"[PDat] AND "humans"[MeSH Terms])
125	**Social responsibility** AND accountability AND **HIV**	PubMed	10/26/14	102	("social responsibility"[MeSH Terms] OR ("social"[All Fields] AND "responsibility"[All Fields]) OR "social

	(limit by last 5 years and humans)				responsibility"[All Fields]) AND ("social responsibility"[MeSH Terms] OR ("social"[All Fields] AND "responsibility"[All Fields]) OR "social responsibility"[All Fields] OR "accountability"[All Fields]) AND ("hiv"[MeSH Terms] OR "hiv"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
126	**Social responsibility** AND accountability AND **HIV** AND **border** (no limitations)	PubMed	10/26/14	1	*Sister cities and easy passage: HIV, mobility and economies of desire in a Thai/Lao border zone* Social Science & Medicine, 2002
127	**Social responsibility** AND accountability AND **border** (no limitations)	PubMed	10/26/14	26	("social responsibility"[MeSH Terms] OR ("social"[All Fields] AND "responsibility"[All Fields]) OR "social responsibility"[All Fields]) AND ("social responsibility"[MeSH Terms] OR ("social"[All Fields] AND "responsibility"[All Fields]) OR "social responsibility"[All Fields] OR "accountability"[All Fields]) AND border[All Fields]
128	**Social responsibility** AND accountability AND **border** (limit by last 5 years and humans)	PubMed	10/26/14	8	("social responsibility"[MeSH Terms] OR ("social"[All Fields] AND "responsibility"[All Fields]) OR "social responsibility"[All Fields]) AND ("social responsibility"[MeSH Terms] OR ("social"[All Fields] AND "responsibility"[All Fields]) OR "social responsibility"[All Fields] OR "accountability"[All Fields]) AND border[All Fields] AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
129	Health Insurance Portability and Accountability Act	PubMed	10/26/14	594	("health insurance portability and accountability act"[MeSH Terms] OR ("health"[All Fields] AND "insurance"[All Fields] AND "portability"[All Fields] AND "accountability"[All Fields] AND "act"[All Fields]) OR "health insurance portability and accountability act"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])

130	Health Insurance Portability and Accountability Act AND HIV services (limit by last 5 years and humans)	PubMed	10/24/14	1	*Removing legal barriers to high-quality care for HIV-infected patients* 2012 New England Journal of Medicine
131	Health Insurance Portability and Accountability Act AND HIV (limit by last 5 years and humans)	PubMed	10/26/14	5	("health insurance portability and accountability act"[MeSH Terms] OR ("health"[All Fields] AND "insurance"[All Fields] AND "portability"[All Fields] AND "accountability"[All Fields] AND "act"[All Fields]) OR "health insurance portability and accountability act"[All Fields]) AND ("hiv"[MeSH Terms] OR "hiv"[All Fields]) AND ("2009/10/28"[PDat] : "2014/10/26"[PDat] AND "humans"[MeSH Terms])
132	Health Insurance Portability and Accountability Act AND border (no limitations)	PubMed	10/26/14	1	*Analyzing privacy requirements: a case study of healthcare in Saudi Arabia* Informatics for Health and Social Care, 2014

Appendix G: Definition of HSUM terms based on results of MMLR process

#	Article	Summary of article	Supporting Quote	HSUM construct definition
	ACCOUNTABILITY			
1.	Chris Dimick. (March 2011). HIPAA violation? Sue me. *Journal of the American Health Information Management Association*.	There are variations in the extent to which jurisdictions are accountable to their constituents in assuring that patient confidentiality is not breached when medical records are shared. Some states limit damages, discourage frivolous lawsuits, or shorten the statutes of limitation.	*"States considering malpractice reform have enacted or are considering multiple options: limiting damages, adding procedural requirements intended to discourage "frivolous" lawsuits, and shortening statutes of limitation."*	In addition to a provider's malpractice insurance, states often cover excess damages. However states may differ in how they provide malpractice compensation.
2.	Morris S, Fleming J, LaFleur S. (Winter 2010). How to protect medical confidentiality when under subpoena. *HIV Clinician*, Vol. 22(1), 7-8.	This article discusses state variation in laws related to the right to medical confidentiality and the implications related to disclosure of HIV positive status. In most cases, if a patient's attorney does not take action to prevent records from being subpoenaed, or take action to object or quash the subpoena, a medical provider may be legally obligated to produce a patient's records.	*"Under the Health Insurance Portability and Accountability Act (HIPAA), "covered entities" must protect the privacy of individuals' medical records. A covered entity includes doctors, nurses, hospitals, clinics, pharmacies, and nursing homes, among others. Violations of HIPAA, and/or the state statues cited below, could result in criminal and civil consequences."*	Medical providers and other covered entities have a responsibility to protect the privacy of individuals' medical records, and assure patient confidentiality.
3.	O'Connor J and Matthews G. (2011). The Private, Personal, and Traditional Sides of Public Health: Informational Privacy, Public Health, and State Laws. *American Journal*	State laws affecting privacy, confidentiality, security, use, and disclosure of information may act as barriers to sharing of information across jurisdictions.	"*Although this* [prohibiting disclosure of personally identifiable health information from one state agency to another] *may be an important protection, this approach may indicate a lost opportunity for collaboration between the health care delivery and financing system and public health*	A state is accountable to its constituents to develop laws protecting individuals' health and medical information, and also to manage disease outbreak collaboratively with bordering states.

#	Article	Summary of article	Supporting Quote	HSUM construct definition
	of Public Health, Vol. 101 (10): 1845-1850.		*authorities seeking to design or deliver interventions for at-risk populations*."	
4.	Szent-Gyorgyi LE, Desai S, Kim D, Sax PE, Greenberg JO. (2012). Removing legal barriers to high-quality care for HIV-infected patients. *New England Journal of Medicine*, Vol. 366 (14):1268-1270.	This article defines accountability as a state's responsibility to balance HIV positive patients' privacy protections, while avoiding the creation of barriers to coordinated, patient-centered care, and barriers to monitoring quality of care. The discussion of laws which vary by state indicates that bordering states with different laws about disclosure of HIV-related medical information could have difficulty in working together. Cross-jurisdictional communication through EHRs may be even more complex.	"*HIV-positive patients should be treated in patient-centered, coordinated systems that ensure they receive all elements of care*," and "*concern about privacy has trumped patients' need to receive high-quality, collaborative care"*	States have a responsibility to balance the privacy rights of HIV positive patients, and avoid creating barriers to coordinated, patient-centered care that can be monitored for quality.
5.	Lyttleton C, Amarapibal A. (2002). Sister cities and easy passage: HIV, mobility and economies of desire in a Thai/Lao border zone. *Soc Sci Med*, 54, 505-518.	Two different governments on each side of the border between Mukdahan and Savannakhet met to address HIV/AIDS through cross-jurisdictional collaboration. Sharing of surveillance data and knowledge of effective education, awareness-building, and testing programs were important to all parties. The collaborative found that borders required better definition and that their collective brainstorming would be necessary to address HIV spread in the border region, since border dynamics heighten HIV	"*Mukdahan/Savannakhet is a typical border zone, because the constant destabilization is what makes local people there consistently vulnerable to HIV infection*."	Efforts from government officials on each side of a jurisdictional border are necessary to address regional economies and jurisdictional policies which affect the spread of HIV epidemics, and vulnerability of populations.

#	Article	Summary of article	Supporting Quote	HSUM construct definition
		vulnerability.		
	ACCESSIBILITY			
1.	Aranda-Naranjo B. (2007). The Care System Assessment Project: values-based health care planning and delivery. *J Health Care Poor Underserved,* Vol. 18 (3 Suppl): 244-247.	This article explains how HIV stigma and discrimination affects availability of medical and social support services for PLWH. Planning councils make decisions about allocating funds, but without representation from members of the target populations, these decisions were difficult and may not reflect the values and needs of PLWH. Cultural competence of policy-makers is important in provider access to care for PLWH.	"[Some sites] *had difficulty engaging vulnerable populations on Planning Councils… their lack of input decreased the shared learning that can occur among diverse populations, and the understanding that Planning Council members have of the values and needs of individuals from cultures different from their own."*	Policy-makers who allocate funds for medical and support services could ensure that services are more accessible if they consider the values and needs of PLWH.
2.	Conviser R. (2007). Catalyzing system changes to make HIV care more accessible. *J Health Care Poor Underserved,* Vol. 18 (3 Suppl): 224-243.	The Care Systems Assessment Project was evaluated using RARE on seven dimensions, one of which is service accessibility. Study participants operationalized service accessibility as clinic location, transportation difficulties, inconvenient clinic hours, and lack of child care available during clinic visits. The article also discusses stigma as a barrier to seeking services in minority communities and acceptability of services.	*"Service access problems arose at all three sites as a result of clinic locations and transportation difficulties, but they were exacerbated by clinic hours that were limited to weekdays, making it difficult for working people to use the clinics. The lack of available childcare or coordinated services for women and children also affected accessibility of services."* *"Healthcare providers tended to be either culturally or technically competent, but seldom both."*	Clinic location and hours, transportation, availability of childcare, and stigma all impact accessibility of services. Both cultural and technical competence of providers also influenced decisions about accessing care.
3.	Keesee MS, Natale AP, Curiel HF. (2012). HIV	When delayed entry into care was regressed on several independent	*"Cumulatively, the underlying cause of many identified barriers is information*	Accessibility of services includes awareness of

#	Article	Summary of article	Supporting Quote	HSUM construct definition
	positive Hispanic/Latinos who delay HIV care: analysis of multilevel care engagement barriers. *Soc Work Health Care*, 51, 457-478.	factors, the following were statistically significant: Didn't know requirements to qualify for medical care (.000), Didn't believe that HIV/AIDS medications were available (.000), Thought services would cost too much (.007), Concern that people would think badly of HIV+ status (.010), no insurance (.011), age at intake (.017), and too sick to seek medical services (.031)	*deficit, even though it does not appear to be language related."*	existing services, and knowledge related to eligibility for services. These factors related to accessibility are also affected by stigma and individual beliefs about health.
4.	Servin AE, Muñoz FA, Strathdee SA, Kozo J, Zúñiga ML. (2012). Choosing sides: HIV health care practices among shared populations of HIV-positive Latinos living near the US-Mexico border. *J Int Assoc Physicians AIDS Care,* Vol.11 (6): 348-355.	From this study, we find that factors affecting accessibility of care include: patient-provider relationship, HIV-related stigma, and health insurance, which may be used on both sides of the border. Coordination of healthcare services is a challenge for those in a border region who do not qualify for health insurance.	*"Despite reporting better patient–provider relationships and less HIV-related stigma than those with visits in Tijuana, San Diego patients were twice as likely to make unsupervised changes in their ART regimen"* *"For some populations, binational health care insurance will improve access to care, but for others who do not qualify for insurance, limited and fragmented access to care in the United States will persist."*	Accessibility may relate to health insurance that is available on both sides of a border; the lack of which may mean limited and fragmented access to care. HIV-related stigma and patient-provider relationship also affect access to healthcare for PLWH. (**also HSUM**)
	AVAILABILITY			
5	Axmann A. (1998). Eastern Europe and Community of Independent States. *Int Migr*, Vol. 36(4):587-603.	The study hypothesizes that the two main determinants of increasing STDs in Russia are 1) changes in sexual behavior driven by increased travel, disruption of the family, displaced youth, and new sexual morality; and	*"There are two main determinants of the increasing prevalence of STDs in Russia. First, changes in sexual behavior driven, in part, by factors such as increased travel and migration, disruption of the family units and the*	Availability of healthcare services for STD/HIV for border-crossing populations is affected by availability of government funded clinics which consider patient's

#	Article	Summary of article	Supporting Quote	HSUM construct definition
		2) changes in the structure, availability, and effectiveness of health services. Russia developed a new system of anonymous dermato-venereology clinics (ADVCs) in recognition of patient's need for confidentiality when accessing HIV/STD-related prevention and care.	*displacement of youth, and liberalization and individualization of sexual morality. Second, marked changes in the structure, availability, and effectiveness of health services."* *"A new system of anonymous dermato-venereology clinics (ADVCs) has been developed in Russia based on a recognized need for patient confidentiality, but persons without money are still expected to use the old clinics and produce identity papers, thereby risking legal constraints and sanctions if they have an STD."*	confidentiality concerns.
6	Li D, Chu P, Yang Y, Li S, Ruan Y, Liu Z, Cao X, Lu L, Jia Z. (2012). High prevalence of HIV, syphilis and HCV, and low methadone maintenance treatment in a migrant population in Beijing. *J Addict Med,* Vol.6 (4):311-317.	The full text of this article is unavailable. Based on the abstract, the finding that rates of STDs are higher among migrant populations and methadone maintenance treatment is lower in these populations may indicate that health services are less available or less accessible to migrant populations.	*"The prevalence of HIV, syphilis, and HCV infection was higher, and the use of MMT was lower in the migrant population. The migrant population is a noticeable challenge for HIV prevention and control in Beijing."*	Health services are less available to migrant populations. Migrants had less knowledge of available services, and also tended to have poorer education and employment statuses.
7	Albarrán CR, Nyamathi A. (2011). HIV and Mexican migrant workers in the United States: a review	The Vulnerable Populations Conceptual Model posits that there is a bidirectional relationship between health status and relative risk, and causal, mono-directional relationships,	*"…the construct of resource availability is determined by considering both macro (community, government, policy, system) and micro (individual, family) levels."*	Resource availability is operationalized as socioeconomic status, power differentials (gender inequalities, language

#	Article	Summary of article	Supporting Quote	HSUM construct definition
	applying the vulnerable populations conceptual model. *J Assoc Nurses AIDS Care*, Vol. 22(3):173-185.	1) from health status to resource availability, and 2) from resource availability to relative risk.		barriers, citizenship status), social connectedness or integration (marginalization, lack of family support, societal discrimination) Human capital (income, employment, education, housing), and healthcare (quality, access, transportation and cost barriers)
8	Seeley JA, Allison EH. (2005). HIV/AIDS in fishing communities: challenges to delivering antiretroviral therapy to vulnerable groups. *AIDS Care*, Vol.17 (6):688-697.	Access to testing and treatment facilities is limited for mobile populations because mobility and irregular working hours hinder adherence to treatment regimens.	*"There is a need for approaches to delivery of ART that are not dependent upon a population being stable and urban (or at least close to a clinic or health post)."*	For populations whose lifestyle involves risky work in remote locations, reaching them with HIV prevention and ART will be difficult.
9	Walia K. (2013). Point of care investigations in pediatric care to improve health care in rural areas. *Indian J Pediatr*, Vol.80 (7):576-584.	Often times, quality lab services are unavailable in rural ares. New technologies have made it possible for point of care tests to be performed outside the lab setting and not compromise accuracy and reliability.	*The already available POC tests which are reliable and affordable, like for HIV infection, malaria, syphilis, and some neglected tropical diseases, and POC tests being developed for other diseases if correctly used and effectively regulated after rigorous evaluation, have the potential to make a difference in clinical management and improve surveillance*	Availability of diagnostic tests which are reliable, affordable, and can be performed outside of the lab setting will improve diagnosis and disease management.

#	Article	Summary of article	Supporting Quote	HSUM construct definition
	ACCEPTABILITY[6]			
	Among the 33 articles which surfaced through PubMed searches of controlled variable terms related to acceptability, there were no articles which also qualified as "A" ranked articles for this study. In other words, though articles surfaced which related to the acceptability and the research question in some way, no article related to acceptability and borders, HIV/STD, and health services. This finding shows a gap in the literature, and possibly a reason to modify the existing HSUM model.			Acceptability Patient attitudes towards health and medical services, patient perception of control over health and medical decisions, patient perception of control over privacy of their health and medical information, and the impact of disease stigma on health service utilization
	In the two sources defining components of HSUM prior to this study, the definition of "Acceptability" has varied slightly; however, both definitions include a discussion of culture and ethics. The U.N. definition includes a discussion of confidentiality, which also surfaced in A ranked articles for Accountability (see Accountability articles 1, 2, and 3 above). The other definition by Zuniga and colleagues includes stigma in their definition of acceptability. In this study, stigma surfaced in all "A" ranked articles under the term Accessibility (See Accessibility articles above).			
	Even when reviewing "B" ranked articles, acceptability is not often defined in a way that is relevant to health service utilization (three of eight articles relate to service utilization in some way). However, one common theme across B ranked article titles is the discussion of attitudes towards certain health services or medical interventions (i.e., six of eight articles). Culture and acculturation are topics in three of the eight B ranked articles; perceived control of patients was a topic in two of the eight articles.			
	In conclusion, it seems that Acceptability could be defined as, "***patient attitudes towards health and medical services, patient perception of control over health and medical decisions, patient perception of control over privacy of their health and medical information, and the impact of disease stigma on health service utilization***." Despite the ability to construct this definition, it is clear from the results of the matrix method of literature review that this construct of HSUM should be further explored and defined in the literature before HSUM can be broadly accepted and applied in practice to guide interventions aimed at improving cross-jurisdictional collaboration between HIV prevention organizations.			

[6] There were no "A" ranked articles.

Appendix H: Comparison of HSUM Definition before and after MMLR process

Definition pre-MMLR	Definition based on MMLR
ACCESSIBILITY	**Accessibility** in terms of health systems, HIV, and border
The U.N. General Comment No. 14 defines accessibility as having four overlapping dimensions: "(i) **Non-discrimination**: Health facilities, goods and services must be accessible to all, especially those most vulnerable; (ii) **Physical accessibility**: Health facilities, goods and services must be within safe physical reach to all, especially vulnerable or marginalized groups. This includes adequate access to buildings for persons with disabilities; (iii) **Economic accessibility (i.e. Affordability)**: Health facilities, goods and services must be affordable for all, meaning that payment for services is based on the principle of equity, ensuring that poorer households are not disproportionately burdened with health expenses as compared to richer households; and (iv) **Information Accessibility**: Includes the right to seek, receive, and impart information and ideas concerning health issues, but does not impair the right to have personal health data treated with confidentiality." Sophia Gruskin and colleagues point out that these components require **special attention to the most vulnerable and affected populations**, and found this definition suitable for the field of sexual health (Gruskin, Bogecho, & Ferguson, 2010). Zuniga and colleagues defined availability simply as "**service convenience or affordability**," in their study of healthcare service utilization in the U.S.-Mexico border region. In addition to the thorough definition provided by the U.N., and confirmed by the Gruskin article, the operationalization of accessibility to services as used by Zuniga and colleagues considers factors related to a border region, and therefore, will be	Definition found in both MMLR and pre-MMLR definition: Decisions of policy-makers about how to allocate funds for medical and support (**Economic accessibility / affordability**) services should consider values and needs of PLWH [1]. Clinic location and hours, transportation, and availability of childcare all impact accessibility of services (**Physical accessibility**) [2]. Accessibility of services includes awareness of existing services, and knowledge related to eligibility for services (**Information Accessibility**). HIV-related ***stigma and patient-provider relationship*** (**Non-discrimination**) also affect access to healthcare for PLWH [4]. Definition components unique to MMLR: Both cultural and technical competence of providers also influenced decisions about accessing care [2]. Accessibility is affected by individual beliefs about health [2, 3]. Accessibility may relate to health insurance that is available on both sides of a border; the lack of which may mean limited and fragmented access to care. [4]

very useful for this study. **Client transportation and literacy level of materials provided by health service providers** will also be considered in the definition of accessibility, as was done in the Zuniga study.	
ACCEPTABILITY	**Acceptability** in terms of health systems, HIV, and border
The U.N. General Comment No. 14 defines accessibility as, "**all health facilities, goods and services must be respectful of medical ethics and culturally appropriate, as well as designed to respect confidentiality and improve the health status of those concerned**." Gruskin, Bogecho, & Ferguson emphasize that health facilities, goods and services must be, "**sensitive to sex and life-cycle requirements**," which is also included in the UN definition. The 2006 study by Zuniga and colleagues defined acceptability as, "**how congruent services are with client expectations (cultural**)," and operationalized this definition as **including consideration of social expectations, language needs, client comfort, as well as addressing potential stigmas**.	Definition found in both MMLR and pre-MMLR definition: Patient perception of control over health and medical decisions (**medical ethics**), patient perception of control over privacy of their health and medical information (**confidentiality**), and the impact of disease stigma (**addressing potential stigma**) on health service utilization. Cultural differences, acculturation (**client cultural expectations**) can impact patient perception of acceptability. [7] Definition components unique to MMLR: Acceptability includes patient attitudes towards health and medical services. Border crossing can impact patient perception of acceptability of these services.
ACCOUNTABILITY	**Accountability** in terms of health systems, HIV, and border:
Quality, not accountability, is the fourth component of the U.N. General Comment No.14 essential elements of a rights-based approach to health. Quality is defined as, "**requiring goods and services to be scientifically and medically appropriate and of good quality; specifically, skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water and adequate sanitation**.	Definition found in both MMLR and pre-MMLR definition: Medical providers and other covered entities require policies to assure patient confidentiality [2]. States have a responsibility protect health and medical information privacy (**mechanisms at local level**), and to balance the privacy rights of HIV positive patients. However, states must also avoid creating barriers to coordinated, patient-centered care that can be monitored for quality (**requiring goods and services to be**

[7] Only one of the 31 Acceptability articles related to HIV. This shows a lack of study of HIV and patient acceptability of care. Seeing as acceptability is a major component of and potential barrier to health service utilization, lack of focus on HIV is concerning.

While quality as described in the U.N. General Comment is important, it does not describe the mechanism for assuring quality is provided in all goods and services. For this reason, accountability seems to be a more useful component of the model. Gruskin and colleagues defines *accountability* as "**mechanisms at local, national, regional, and international levels to monitor compliance and support governments in fulfilling their human rights obligations to their populations, which impact on health and development**," (Gruskin, Bogecho, & Ferguson, 2010). The Zuniga models discusses accountability as accountability of services to clients and to the community, which is a much better fit for this discussion of jurisdictional border. According to Zuniga and colleagues, accountability refers to **service system responsiveness to clients and community**. This does not negate, but rather builds on the previously mentioned definitions. The study by Zuniga and colleagues specifically mentions the necessity of **mechanisms for consumers to participate in service decision-making or to provide feedback on services they receive**.	**scientifically and medically appropriate and of good quality**) [4]. Definition components unique to MMLR: State laws must protect health and medical information privacy, while managing disease outbreaks across jurisdictional borders [3]. Efforts from government officials on each side of a jurisdictional border are necessary to address regional economies and jurisdictional policies which affect the spread of HIV epidemics, and vulnerability of populations [5].
AVAILABILITY	**Availability** in terms of health systems, HIV, and border
The General Comment No. 14 definition states that availability means the **existence of public health and healthcare facilities in sufficient quantity**; however, it specifies that "**sufficient quantity" is relative to the region**. The General Comment goes on to explain that services which should be in sufficient quantity to provide health to the public **includes safe drinking water, sanitation facilities, hospitals, clinics, trained medical and professional personnel receiving competitive salaries, and essential drugs** (United Nations Economic and Social Council, Committee on Economic, Social, and Cultural Rights, 2000). Zuniga, et al. also describes availability of services as the	Definition found in both MMLR and pre-MMLR definition: None identified. Definition components unique to MMLR: Availability of healthcare services for STD/HIV for border-crossing populations is affected by ***availability of government funded clinics which consider patient's confidentiality concerns*** [1]. ***Availability of "MSM-friendly" providers*** is also important for treatment adherence (Beckerman A, and Fontana L, 2009). Resource availability is operationalized as ***socioeconomic status,***

existence of services, and has operationalized the definition as, "**Are services available in the geographic area**?" (Zuniga, et al., 2006).	***power differentials*** (gender inequalities, language barriers, citizenship status), ***social connectedness or integration*** (marginalization, lack of family support, societal discrimination) ***Human capital*** (income, employment, education, housing), and ***healthcare*** (quality, access, transportation and cost barriers) [3]. ***Availability of diagnostic tests which are reliable, affordable, and can be performed outside of the lab setting*** will improve diagnosis and disease management [5]. ***Organization characteristics can contribute to high turnover and staff shortages, thus compromising availability of services*** (Dill, Cagle 2010). Kenya has a Health Workforce Information System (KHWIS), which helps Kenya to ensure that health services are available for the public through ***health worker regulation***, ***human resources management*** and ***workforce policy and planning*** (Waters KP, Zuber A, Wiley RM, et al., 2013). Brain drain: Several articles discuss health care service availability being affected by migration of health care workers from low-income to high-income nations (Yamamoto, et al. 2012). Reasons for health care worker migration have been evaluated, and appear to be motivated by more than just salary (Willis-Shattuck M, Bidwell P, et al., 2008). Fewer qualified students applying to hospitals for residency presents a challenge in availability of ***quality health care workers*** (Schmidt K, et al., 2012). The knowledge, skills, and competencies of a workforce prepared to deliver effective interventions; the efficient and effective organization of work; and the development and replication of effective workforce training and support strategies to sustain effective services are necessary to make health services available to the public (Schoenwald SK, 2010).

Appendix I: HSUM constructs with sub-constructs

Accessibility	Acceptability	Accountability	Availability
• Allocations of funding • Clinic location • Clinic hours • Transportation, • Availability of childcare • Awareness of existing services and eligibility • HIV-related stigma and patient-provider relationship • Cultural competence of providers • Technical competence of providers • Differences in health attitudes and beliefs • Health insurance access	• Medical ethics • Perception of control over health and medical decisions • Confidentiality of health and medical information • Impact of disease stigma • Cultural differences between patient and provider • Patient attitudes towards health services	• Mechanisms to protect privacy of health and medical information • Mechanisms to monitor quality of care. • Government agreement on policies affecting HIV epidemics and vulnerable populations. • Mechanisms for consumers to participate in service decision-making • Mechanisms for patients to provide feedback on services	• Number of clinics which respect patient privacy concerns • Number of MSM-friendly providers • Power differentials • Social connectedness • Human capital • Availability of reliable, affordable diagnostic tests • Organization characteristics such as staff turnover and shortages • Data systems for communication about available services and resources • Data systems for oversight of health care workforce • Health care worker migration.

References

Gerrard, J. (2011). Health sciences literature review made easy: The matrix method. Sudbury, MA: Jones & Bartlett.

Goldman KD and Schmalz KJ. (2004). The Matrix Method of Literature Reviews. Health Promotion and Practice. Vol. 5(1): 5-7.

Gallicano, Tiffany. July 22, 2013. "An example of how to perform open coding, axial coding, and selective coding." The PR Post. University of Oregon. Available at: http://prpost.wordpress.com/2013/07/22/an-example-of-how-to-perform-open-coding-axial-coding-and-selective-coding/

Hwang, Sungsoo. (2008). Utilizing Qualitative Data Analysis Software: A Review of Atlas.ti. *Social Science Computer Review*. Vol. 26(4):519-527.

National Association of County & City Health Officials. (January 2014). 2013 National Profile of Local Health Departments Report.

Richard A. Krueger & Mary Anne Casey. (2000). Focus Groups: A Practical Guide for Applied Research, 3rd ed. Sage Publications, Inc.

John W. Creswell and Vicki L. Plano Clark. (2011). Designing and Conducting Mixed Methods Research, 2nd ed. Sage Publications.

Pricilla R. Ulin, Elizabeth T. Robinson, and Elizabeth E. Tolley. (2005). Qualitative Methods in Public Health: A Field Guide for Applied Research. Jossey-Bass, San Francisco, CA.

Leech NL, Onwuegbuzie A J. (2007). An array of qualitative data analysis tools: A call for data analysis triangulation. School Psychology Quarterly, Vol. 22(4), 557-584.

Cohen J. (1960). A coefficient of agreement for nominal scales. Educational and Psychological Measurement, 20:37-46.

Landis JR and Koch GG. (1977). The measurement of observer agreement for categorical data. Biometrics, 33:159-74.

Viera AJ and Garrett JM. (2005). Understanding Interobserver Agreement: The Kappa Statistic. Family Medicine, Vol. 37 (5): 360-363.

Stefl ME & Prosperi DC. (1985). Barriers to mental health service utilization. Community Mental Health Journal. Vol. 21 (3): 167-178.

Blank MB, Fox JC, Hargrove DS, Turner JT. (1995). Critical Issues in Reforming Rural Mental Health Service Delivery Community Mental Health Journal. Vol. 31(6):511-524.

Cristina Puentes-Markides. (1992). Women and access to health care. Social Sciences & Medicine, Vol. 35(4):619-626.

Damron-Rodriguez J, Wallace S, and Kington R. (1995). Service Utilization and Minority Elderly: Appropriateness, Accessibility, and Acceptability. Gerontology & Geriatrics Education. Vol. 15(1):45-64.

United Nations Economic and Social Council, Committee on Economic, Social, and Cultural Rights. (2000). Substantive issues arising in the implementation of the international covenant on economic, social, and cultural rights (General Comment No. 14): The right to the highest attainable standard of health (article 12 of the International Covenant on Economic, Social and Cultural Rights). Geneva, 25 April – 12 May, 2000.

Pett, Marjorie A. (1997). Nonparametric Statistics for Health Care Research: Statistics for Small Samples and Unusual Distributions. California: Sage Publications, Inc.

Fredericksen P & London R. (2000). Disconnect in the Hollow State: The pivotal role of organizational capacity in community-based development organizations. Public Administration Review, Vol.60 (3):230-239.

Nu'Man J, King W, Bhalakia A, and Criss S. (2007). A framework for building organizational capacity integrating planning, monitoring and evaluation. Journal of Public Health Management and Practice. Jan (Suppl.):S24-S32.

Powell WW, Koput KW, and Smith-Doerr L. (1996). Interorganizational Collaboration and the Locus of Innovation: Networks of Learning in Biotechnology. Administrative Science Quarterly, 41, 116-145.

Creswell JW, Klassen AC, Plano Clark VL, and Clegg Smith K. (2010). Best practices for mixed methods research in the health sciences. Office of Behavioral and Social Science Research.

Centers for Disease Control and Prevention. (December 2012). Estimated HIV incidence in the United States, 2007–2010. HIV Surveillance Supplemental Report 2012, 17(4), 1-26. Retrieved from http://www.cdc.gov/hiv/pdf/statistics_hssr_vol_17_no_4.pdf

Institute of Medicine, Committee on Public Health Strategies to Improve Health. (2012, April). For the Public's Health: Investing in a Healthier Future, Briefing Slides. Retrieved from www.iom.edu/phfunding

The White House. (2010, July). National HIV/AIDS Strategy for the United States. Retrieved from http://aids.gov/federal-resources/national-hiv-aids-strategy/documents/index.html

Hall HI, Green TA, Wolitski RJ, Holtgrave DR, Rhodes P, Lehman JS, Durden T, Fenton KA, Mermin JH. (2010). Estimated future HIV prevalence, incidence, and potential infections averted in the United States: a multiple scenario analysis. *Journal of Acquired Immune Deficiency Syndrome*, (55.2), 271-6.

Maryland Department of Health and Mental Hygiene, Prevention and Health Promotion Administration. "HIV in Suburban Washington: An epidemiological profile." Presented by Colyn Flynn at the Suburban Regional Advisory Committee Meeting, May 8, 2013.

Mosaica: The Center for Nonprofit Development and Pluralism. (April 2010). The Profiles Project: How the Washington, D.C. Suburbs Respond to HIV/AIDS. Retrieved from http://www.washingtongrantmakers.org/s_wash/bin.asp?CID=4603&DID=42317&DOC=FILE.PDF

Wallace R & Wallace D. (1995). U.S. apartheid and the spread of AIDS to the suburbs: a multi-city analysis of the political economy of spatial epidemic threshold. Social Science Medicine. (41.3), 333-45.

Maryland Department of Health and Mental Hygiene, Maryland HEZ Supplemental Data Viewer. *Total Living HIV Case Rate.* Available online: http://dhmh.maryland.gov/healthenterprisezones/SitePages/Hez_Resources.aspx Accessed June 3, 2013.

King, Chris. (2007). Recommendations for HIV prevention in Prince George's County, Maryland.

Wooster J, Eshel A, Moore A, Mishra M, Toledo C, Uhl G, and Wright-DeAguero L. (2011). Opening up their doors; perspectives on the involvement of the African American faith community in HIV prevention in four communities. *Health Promotion Practice*, Vol. 12(5):769-778.

Brooke DeRenzis and Alice M. Rivlin. (2007). A Pathway to the Middle Class: Migration and Demographic Change in Prince George's County. The Brookings Institution, Greater Washington Research Program. April 2007.

Allard SW and Roth B. (2010). Strained Suburbs: The Social Service Challenges of Rising Suburban Poverty. Brookings Institution, Metropolitan Opportunity Series.

George Mason University (GMU) Center for Regional Analysis (CRA). "Update from the American Community Survey: Poverty in the Washington DC Metropolitan Area." CRA Census Series. November 2011. Available online: http://cra.gmu.edu/pdfs/researach_reports/recent_reports/2010_Poverty.pdf

U.S. Census Bureau. (2012). *State and County Quick Facts: Prince George's County, MD*. Retrieved from http://quickfacts.census.gov/qfd/states/24/24033.html Accessed: June 11, 2013. Last Revised: Thursday, 06-Jun-2013 12:09:11 EDT.

Prince George's County Health Department. (2012). Prince George's County Health Enterprise Zone: Primary Care – Public Health Integrated Services Model (proposal to the State of Maryland Community Health Resources Commission). Retrieved from http://dhmh.maryland.gov/healthenterprisezones/SitePages/Updates.aspx

American Social Health Association (ASHA). (2008). *Show Me the Money: State Investment in STD Prevention*, FY 2007. Research Triangle Park: ASHA.

Sarpal N. (2009). Development of STI Prevention Policy Recommendations for Baltimore City. (Unpublished MPH Project). University of Maryland, College Park.

Harper KN, Zuckerman MK, Harper ML, Kingston JD, and Armelagos GJ. (2011). The origin and antiquity of syphilis revisited: An Appraisal of Old World pre-Columbian evidence for treponemal infection. American Journal of Physical Anthropology Supplement: Yearbook of Physical Anthropology. Vol. 146 (S53): 99–133

Zuniga ML, Blanco E, Palinkas LA, Strathdee SA, and Gifford AL. (2010). Cross-cultural considerations in the recruitment of Latinos of Mexican origin into HIV/AIDS Clinical Trials in the U.S.-Mexico Border Region: Clinician and Patient Perspectives. Journal of Immigrant and Refugee Studies, Vol. 8: 241-260.

Anderson RM. (1995). Revisiting the behavioral model and access to medical care: Does it matter? Journal of Health and Social Behavior. Vol. 36: 1-19.

Sangaramoorthy, Thurka. (2008). Invisible Americans: Migration, Transnationalism, and the Politics of Difference in HIV/AIDS Research. *Studies in Ethnicity and Nationalism*, Vol. 8(2):248-266.

World Health Organization. (2003). Partnership work: the health service-community interface for the prevention, care and treatment of HIV/AIDS. Edited by Hedwig Goede and Walid El Ansari. A report of the WHO Consultation Dec. 5-6 2002, Geneva, Switzerland.

Centers for Disease Control and Prevention. Program Collaboration and Service Integration: Enhancing the Prevention and Control of HIV/AIDS, Viral Hepatitis, Sexually Transmitted Diseases, and Tuberculosis in the United States. Atlanta (GA): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2009.

Tullberg, Jan. (2013). Stakeholder Theory: Some revisionist suggestions. Journal of Socio-Economics, Vol. 42, 127-135.

Gruskin S, Bogecho D, Ferguson L. (2010). Rights-based approaches to health policies and programs: Articulations, ambiguities and assessment. Journal of Public Health Policy, Vol.31, 129-145.

Gruskin S. (2008). Reproductive and Sexual Rights: Do Words Matter? American Journal of Public Health. Vol. 98(10): 1737-1737.

Blank MB, Fox JC, Hargrove DS, Turner JT. (1995). Critical Issues in Reforming Rural Mental Health Service Delivery Community Mental Health Journal. Vol. 31(6):511-524.

Ingram M, Gallegos G, Elenes J. (2005). "Diabetes is a Community Issue: The Critical Elements of a Successful Outreach and Education Model on the U.S.-Mexico Border." *Preventing Chronic Disease: Public Health Research, Practice and Policy.* Jan; 2(1):1-9.

Cohen SJ, Ingram M. (2005). "Border Health Strategic Initiative: Overview and Introduction to a Community-based Model for Diabetes Prevention and Control." *Preventing Chronic Disease: Public Health Research, Practice and Policy.* Jan; 2(1):1-9.

Steinfelt VE. (2005). "The Border Health Strategic Initiative from a Community Perspective." *Preventing Chronic Disease: Public Health Research, Practice and Policy.* Jan; 2(1):1-5.

Desrochers, S. (2002). Measuring work-family boundary ambiguity: A proposed scale. Bronfenbrenner Life Course Center Working Paper #02-04.

Orozco-Mendoza EF. (2008). Borderlands Theory: Producing Border Epistemologies with Gloria Anzaldua. (Master's Thesis). Virginia Polytechnic Institute and State University. Blacksburg, VA.

Naples NA. (2009). Borderlands Studies and Border Theory: Linking Activism and Scholarship for Social Justice. Compass Interdisciplinary Virtual Conference, October 19-30, 2009.

Naples NA. (2009a). "Crossing Borders: Community Activism, Globalization, and Social Justice." Social Problems 56(1):2–20.

Aunio AL. (2009). Commentary On: Borderlands Studies and Border Theory: Linking Activism and Scholarship for Social Justice. Compass Interdisciplinary Virtual Conference, October 19-30, 2009.

Vila, Pablo. 2003. "The Limits of American Border Theory." Pp. 306-41 in *Ethnography at the border*, edited by Pablo Vila. Minneapolis, MN: University of Minnesota Press.

Anzaldúa, Gloria. 1987. Borderlands/La Frontera: the new mestiza. San Francisco, CA: Spinsters/Aunt Lute.

Fox C, Guglielmo TA. (2012). Defining America's Racial Boundaries: Blacks, Mexicans, and European Immigrants, 1890-1945. American Journal of Sociology, Vol. 118(2): 327-379.

Matthews RA, Barnes-Farrell JL. (2010). Development and Initial Evaluation of an Enhanced Measure of Boundary Flexibility for the Work and Family Domains. Journal of Occupational Health Psychology, Vol. 15(3): 330-346.

Bernasconi R. (2012). Crossed Lines in the Racialization Process: Race as a Border Concept. Research in Phenomenology, Vol. 42, 206-228.

Maryland HIV/AIDS Epidemiological Profile, Fourth Quarter 2012, Data reported through December 31, 2012, Center for HIV Surveillance, Epidemiology and Evaluation, Infectious Disease Bureau, Prevention and Health Promotion Administration, Maryland Department of Health and Mental Hygiene http://phpa.dhmh.maryland.gov/oideor/chse

Maryland Department of Health and Mental Hygiene. (October 2012). Maryland SHIP: State Health Improvement Process, 2012 Update. Available at: http://dhmh.maryland.gov/ship

Sumartojo E. Structural factors in HIV prevention: concepts, examples, and implications for research. AIDS. 2000; 14:S3-S10.

Rhodes T, Wagner K, Strathdee SA, Shannon K, Davidson P, & Bourgois P. (2012). Structural violence and structural vulnerability within the risk environment: Theoretical and methodological perspectives for a social epidemiology of HIV risk among injection drug users and sex workers. In: O'Campo P, Dunn, JR, ed. Rethinking Social Epidemiology: Towards a Science of Change. Dordrecht, Netherlands: Springer, 2012:205-230. Retrieved from: http://link.springer.com/chapter/10.1007%2F978-94-007-2138-8_10#page-1

Aday LA. At Risk in America: The Health and Health Care Needs of Vulnerable Populations in the United States. 2nd ed. San Francisco: Jossey-Bass, 2003.

National Association of County & City Health Officials. (2013). 2013 National Profile of Local Health Departments. *Jan Wilhoit,* Retrieved from http://www.naccho.org/topics/infrastructure/profile/upload/2013-National-Profile-of-Local-Health-Departments-report.pdf

Metropolitan Washington Regional Ryan White Planning Council (2012). Washington DC Regional Eligible Metropolitan Area 2012-2014 Comprehensive HIV Care Plan. Washington DC. Retrieved from http://doh.dc.gov/publication/comprehensive-hiv-care-plan-2012-2014

Daniel Stokols. (1996) 'Translating Social Ecological Theory into Guidelines for Community Health Promotion.' American Journal of Health Promotion, Vol. 10(4):282-98. Source: https://webfiles.uci.edu/dstokols/Pubs/Translating.PDF

European Observatory on Health Systems and Policies. "Cross-border Health Care in the EU: Mapping and analyzing practices and policies."

Moya EM, Loza O and Lusk M. (2012). "Border Health: Inequities, Social Determinants, and the Cases of TB and HIV." Book Chapter in: Social Justice in the U.S. Mexico Border Region.

Questionnaire by the Istituto di Sociologia Internazionale di Gorizia (ISIG). Published by the United Nations Economic and Social Council (2009).

Dente MG et al. (2009). “EpiSouth: a network for communicable disease control in the Mediterranean region and the Balkans.” European Surveillance.

Busse, Worz, Foubister, Mossialos, and Berman. (Nov. 2006). Mapping Health Services Access: National and Cross-border Issues (HealthACCESS).

MacPherson DW and Gushulak BD. (2001). Human mobility and population health: new approaches in a globalizing world. Perspectives in Biology and Medicine, Vol. 44(3): 390-401.

Latkin C, Weeks M, Glasman L, Galletly C, Albarracin D. (2010). A dynamic social systems model for considering structural factors in HIV prevention and detection. AIDS Behavior, Vol. 14 (Suppl. 2): 222-238.

Marshall JB. (2012). An analysis of geography project data to determine HIV and behavioral risk for high risk zip codes and low risk zip codes in Fulton County, GA. (Master’s Thesis). Retrieved from ProQuest database. (Georgia State University, Paper 234).

Pam B. Creekmur & Fran Preneta. (2012). Prince George’s County Health Improvement Plan 2011 to 2014: Blueprint for a Healthier County. Available online: http://www.sph.umd.edu/umdprc/docs/LocalhealthPlanPrefinal.pdf

MacPherson DW, Gushulak BD. (2001). Human mobility and population health: new approaches in a globalizing world. Perspectives in Biology and Medicine, Vol. 44(3): 390-401.

Centers for Disease Control and Prevention. (2011). HIV Surveillance Report, Vol. 23.

Brown, E. (2012, December 12). D.C. releases results of nation’s first-ever standardized test on health and sex ed. *Washington Post Local*. Retrieved from http://www.washingtonpost.com/blogs/dc-schools-insider/post/dc-releases-results-of-nations-first-ever-standardized-test-on-health-and-sex-ed/2012/12/12/c52da276-4494-11e2-8061-253bccfc7532_blog.html

Noble, KB. (1988, August 6). Company halting health plan on some “Life Style” illnesses. *The New York Times*. Retrieved from http://www.nytimes.com/1988/08/06/us/company-halting-health-plan-on-some-life-style-illnesses.html

McLeroy KR, Bibeau D, Steckler A, and Glanz K. (1988). An ecological perspective on health promotion programs. *Health Education Quarterly*, Vol. 15(4):351-377.

McQuiston C, Choi-Hevel S, Clawson M. (2001). Protegiendo Nuestra Comunidad: empowerment participatory education for HIV prevention. Journal of Transcultural Nursing, Vol. 12(4): 274-283.

Weiner BJ, Lewis MA, Clauser SB, Stitzenberg KB. (2012). In search of synergy: Strategies for combining interventions at multiple levels. *Journal of the National Cancer Institute Monograph*, 44: 34-41.

Washington D.C. Department of Health. (2012, November 14). The DC Comprehensive HIV Prevention Plan 2012-2015. Retrieved from http://doh.dc.gov/publication/dc-comprehensive-hiv-prevention-plan-2012-2015

Maryland Department of Health & Mental Hygiene, Prevention and Health Promotion Administration. (2012 September). 2012-2014 Maryland HIV Plan: Comprehensive HIV Plan, Statement of Need, Maryland HIV Prevention Plan. Retrieved from http://phpa.dhmh.maryland.gov/OIDPCS/CHP/SiteAssets/SitePages/regional-advisory-committee/Maryland%202012-2014%20HIV%20Plan.pdf

Boekeloo BO. Faculty Engagement with the University of Maryland Prevention Research Center, Faculty Assembly, University of Maryland School of Public Health, 2009. (Presentation).

Wright M. (2006). Disposable Women and Other Myths of Global Capitalism. Taylor & Francis Group, LLC.

Nancy A. Naples (2010). Review of Kathleen Staudt 'Violence and Activism at the Border: Gender, Fear, and Everyday Life in Ciudad Juárez' Perspectives on Politics, 8, pp 1202-1203. doi:10.1017/S1537592710002999.

Staudt, Kathleen A. (2008). Violence and Activism at the Border: Gender, Fear, and Everyday Life in Ciudad Juarez. United States: University of Texas Press.

Soskolne V and Shtarkshall RA. (2002). Migration and HIV prevention programs: linking structural factors, culture, and individual behavior – an Israeli experience. Social Science and Medicine, 55, 1297-1307.

Health Resources and Services Administration, HIV/AIDS Program. (2014). About Part A: Grants to Emerging Metropolitan & Transitional Grant Areas. (Website). Retrieved from http://hab.hrsa.gov/abouthab/parta.html

Patrick Libbey and Bruce Miyahara. (Jan. 2011). Cross-jurisdictional relationships in local public health. Robertwood Johnson Foundation.

Tawil O, Verster A, O'Reilly KR. Enabling approaches for HIV/AIDS prevention: can we modify the environment and minimize the risk? AIDS 1995; 9(12):1299–1306.

Parker RG, Easton D, Klein CH. Structural barriers and facilitators in HIV prevention: a review of international research. AIDS 2000; 14 1:S22–S32.

Gupta GR, Parkhurst JO, Ogden JA, Aggleton P, Mahal A. Structural approaches to HIV prevention. Lancet 2008; 372(9640):764–775.

Feldacker CB. (2009). Is it who you are or where you live? A mixed-method exploration of associations between people and place in the context of HIV in rural Malawi (Published Dissertation). University of North Carolina. Proquest database.

Landis JR and Koch GG. (1977). The measurement of observer agreement for multiple attribute responses. *Biometrics*,45: 957-967.

Schulman S. (2006). Wither deliveration? Mass e-mail campaigns and U.S. regulatory rulemaking. *Journal of E-Government*, Vol. 3(3):41-64.