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Portia Thomas

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Exploring Men who have sex with men's HIV Pre-exposure Prophylaxis  
Initiation Decision-making Processes in the Southern United States

by

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Submitted in Partial Fulfillment for the Requirement of

Doctorate of Nursing Science

Kennesaw State University

WellStar College of Health and Human Services

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2018

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### **Abstract**

In 2012, the first pharmacological HIV preventative agent, pre-exposure prophylaxis (PrEP) was approved in the U.S. for individuals at high-risk of contracting HIV. Men who have sex with men (MSM) are at increased HIV risk, due to their engagement in anal intercourse (AI), which is the most common mode of HIV transmission and the riskiest type of sex. Although evidence indicates that most PrEP patients are MSM, a paucity of evidence exists on MSM's PrEP initiation decision-making process. The purpose of this study was to explore how HIV-negative MSM engaging in protected or unprotected AI decide to initiate PrEP based on the evaluation and perceptions pertaining to their: (a) PrEP knowledge and HIV risk(s)/concern(s); (b) personal and social motivations to initiate PrEP; and (c) behavioral skills and abilities to adhere to PrEP. Guided by the Information-Motivation Behavioral (IMB) skills model, a six-item questionnaire was constructed and used to conduct one-on-one semi-structured interviews. Fourteen MSM (71% African-American) living in the Southern U.S. consented to an interview between March and August of 2018. Several themes emerged from the inductive content analysis, and these themes were categorized into five broader concepts: (1) acknowledged HIV-risks, (2) HIV concerns, (3) PrEP understanding, (4) PrEP accessibility, and (5) PrEP consideration. On further analysis, the data revealed the PrEP Initiation Decision-making (PID) model, a conceptualization of this sample's non-linear thoughtful process of weighing and evaluating their perceptions and attitudes surrounding these five factors in deriving at their decision to initiate PrEP. The findings give insight into the PrEP initiation decision-making process of an HIV-vulnerable population. Knowledge of patients' rationale and decision-making process for initiating PrEP allows nursing professionals to provide in-depth PrEP patient education, ensuring that patients receive accurate and complete PrEP information including the (1) relationship between adherence and efficacy;

(2) utilization of traditional risk-reduction behaviors in conjunction with PrEP; and (3) the availability of financial assistance programs. This study's evidence is foundational, establishing a knowledge base for PrEP initiation inquiries in the MSM and other PrEP patient populations in the U.S.

*Keywords:* HIV prevention, MSM, HIV pre-exposure prophylaxis, PrEP, decision-making

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Exploring Men who have sex with men's HIV Pre-exposure Prophylaxis  
Initiation Decision-making Processes in the Southern United States

Chapter 1: Introduction

The incidence of human immunodeficiency virus (HIV) in the United States (U.S.) disproportionately affects men who have sex with men (MSM). MSM make up less than 3% of the U.S. population (Ward, Dahlgamer, Galinsky, & Joestl, 2014), but represent 56% of people living with HIV (PLWH) (Centers for Disease Control & Prevention [CDC], 2018a). Despite a national HIV incidence decline of 19% between 2005 and 2014, MSM's incidence rose by 6% during that same nine-year period (CDC, 2016c). Additionally, fifty thousand new cases of HIV are reported annually in the U.S., and MSM continually account for majority of these cases. In 2016, MSM accounted for 82% and 67% of new HIV infections among men and nationally, respectively (CDC, 2018a). MSM's HIV incidence rate is 44 times higher than in men engaging in heterosexual intercourse or injection drug use (IDU) and 40 times higher than in women (CDC, 2016d). If the incidence continues at the current rate, the CDC (2016c) estimates that 1 in 6 MSM will contract the virus in their lifetime.

HIV is the virus that causes acquired immune deficiency syndrome (AIDS), an incurable and potentially fatal disease. AIDS' morbidity and mortality occurs when the virus proliferates in the body, attacking CD4 cells (Fan, Conner, & Villarreal, 2014). CD4 cells are important white blood cells that fight infections; a depleted or low CD4 count damages the body's immune system, increasing one's risk of acquiring and dying from an AIDS induced opportunistic infection or complication (Fan et al., 2014). Advances in HIV treatment through antiretroviral therapy (ART) reduces HIV/AIDS related morbidity and mortality, as it works to decrease the viral load, the amount of virus circulating in the body to a low or undetectable level (AIDS Info,

2017b). A low or undetectable viral load is imperative for PLWH to live a long and optimal life. ART increases life expectancy, as data show that between 2000 and 2007 the number of years lived post-ART for PLWH increased from 36.1 to 51.4 years (Samji et al., 2013). Barring additional co-morbidities, PLWH diagnosed and treated early and consistently with ART have a life expectancy equivalent to those of the general population (Nakagawa, May, & Phillips, 2013; Romley et al., 2014; Samji et al., 2013).

Unfortunately, not all PLWH achieve this optimal outcome, as in the absence of ART, HIV progresses to AIDS. Data show that only 30% of PLWH have a low or undetectable viral load count (Center for AIDS Information and Advocacy [CFA], 2015; CDC, 2016b, 2016f), and this statistic contributes to the HIV/AIDS related mortality apparent in the U.S. AIDS still claims the lives of 13,000 people each year in the U.S. (CDC, 2016c; Fan et al., 2014). Similar to the HIV incidence, no other group is affected more by AIDS than MSM. MSM accounted for 54% of AIDS diagnoses in 2014 (CDC, 2016c), and since the start of the epidemic, MSM have accounted for more than 360,000 (CDC, 2017b) of the 675,000 AIDS deaths (CDC, 2016f). HIV prevention is the key to decreasing AIDS deaths, and the current and predicted HIV incidence in the MSM population (CDC, 2016c; Fan et al., 2014).

The MSM population experiences significant HIV burden and vulnerability. MSM's sexual behaviors are the primary catalyst driving their HIV incidence disparity. MSM are men who engage in anal intercourse (AI), protected or not, with other men, and most MSM report engaging in protected and unprotected AI (UAI) (Meng et al., 2015). Although MSM are also at HIV risk when engaging in oral sex with men and women, vaginal/AI with women, and IDU, AI is the greatest risk factor for contracting and transmitting the disease. Overall, AI in MSM is the most common mode of HIV transmission, as IDU accounts for the smallest percentage of new

and existing HIV cases (CDC, 2016d). Additionally, AI is the riskiest type of sex, as HIV risk with AI is 18 times higher than vaginal intercourse (CFA, 2014; Pebody, 2010). HIV risk is significantly higher because rectal tissue is fragile and thin that easily tears during AI, which allows viral transmission through rectal tissue and penile openings, scratches, or sores (CDC, 2016a). Although both partners are at high HIV risk, the receptive partner has an HIV risk 6.2 times higher than the insertive partner (Meng et al., 2015). Therefore, accurate and consistent condom use is the best defense to prevent new HIV infections (CDC, 2015c, 2016c). During AI, male condom use significantly decreases HIV risk by 63% for the insertive partner, and 72% for the receptive partner (CDC, 2015c). Unfortunately, MSM's condom use adherence is an ongoing challenge; a secondary analysis utilizing data from two previously conducted prospective studies sampling HIV-negative MSM concluded that only 16% of MSM report consistent condom use with each sexual encounter (Smith, Herbst, Zhang, & Rose, 2015).

MSM HIV prevention efforts have focused on interventions promoting individual behavioral changes in both HIV positive and negative persons (CDC, 2015a). Using peers or health professionals in virtual or in-person settings, individual interventions provide counseling and information about utilization of HIV risk-reduction behaviors through problem solving and skill building (CDC, 2015a, 2017a). In addition to consistent condom-use, other risk-reduction behaviors include decreasing sexual partners, serosorting (having unprotected sex only with persons with the same HIV status), avoiding sex cognitively impaired, substance abuse treatment, and abstinence (Caceres et al., 2015; CFA, 2014; CDC, 2016c). For the purposes of this paper, the investigator will refer to the aforementioned behaviors collectively as traditional HIV prevention behaviors. A combination of traditional behaviors is recommended for optimal HIV protection (Caceres et al., 2015; CFA, 2014; CDC, 2016c). Interventions targeting



individual behavior changes are best practices to increasing MSM's and other individuals' risk-reduction behaviors (CDC, 2014a). Despite these best practices, the MSM HIV incidence rate and epidemic are a public health concern. As a result, HIV scientists and researchers developed a new preventative modality (CDC, 2014b).

### **HIV Pre-exposure Prophylaxis (PrEP)**

In July 2012, the U.S. Food and Drug Administration (FDA) approved the first pharmacological HIV preventative regimen. Pre-exposure prophylaxis (PrEP) is the fixed daily dose of Truvada (emtricitabine and tenofovir disoproxil fumarate) in HIV-negative persons 18 years of age and older (CDC, 2014b), and in May 2018, the FDA approved PrEP for adolescents and persons under 18 years of age weighing at least 35kg or 77lbs (CDC, 2018b). Truvada is a nucleoside reverse transcriptase inhibitor (NRTI), initially approved in 2004 for HIV ART; however, Truvada as PrEP is used for HIV prevention to reduce transmission risk (CDC, 2014b). Clinical trial data showed that in the event of an exposure, PrEP is efficacious, reducing the risk of HIV seroconversion by as much as 92% (CDC, 2014b), but it has limitations. Adherence to the daily regimen is necessary to achieve optimal efficacy (CDC, 2014b; Koenig, Lyles, & Smith, 2013). Additionally, Truvada does not provide invincibility to HIV transmission; therefore, PrEP is a complementary regimen, recommended to be used in conjunction with other traditional HIV risk-reduction behaviors, especially consistent condom use (CDC, 2014b).

PrEP is clinically indicated for HIV-negative persons with reported and documented high HIV-acquisition risks (CDC, 2014b). Due to MSM's HIV incidence and vulnerabilities, MSM is a population with PrEP clinical indications. Specifically, PrEP is appropriate for MSM when their sexual history confirms: (a) one or more bacterial sexually-transmitted infections (STIs) in the past six months, (b) multiple sex partners, (c) inconsistent or no condom use with vaginal or

anal sex, (d) work as a commercial sex worker, (e) involved in a serodiscordant relationship, or (f) frequent non-occupational post-exposure prophylaxis (nPEP) treatment (receiving ART after a suspected or known sexually related exposure to HIV) (CDC, 2014b).

PrEP initiation has remained slow nationally (Mayer et al., 2015; Siemieniuk et al., 2015). Utilizing a representative U.S. sample, the CDC (2015d) determined that 25% of MSM have PrEP indications. Gilead®, the pharmaceutical maker of PrEP, surveyed U.S. retail pharmacies about the number of patients that filled a PrEP prescription for the first time during 2012 to 2015 and found that most patients initiating PrEP to be male (76%) and White (74%) (National AIDS Manual [NAM], 2018). Additional data indicate that most current and former PrEP patients are MSM (Krakower et al., 2015; Rooney, 2013; Tellalian, Maznavi, Bredeek, & Hardy, 2013), but that only accounts for a small percentage of this HIV-vulnerable population. Data show that approximately 3% of the MSM population are, or have initiated PrEP (Krakower et al., 2015; Krakower & Mayer, 2015; Tellalian et al., 2013). These descriptive statistics regarding PrEP patients confirm that despite PrEP's indications and efficaciousness, initiating the complementary regimen is an individual choice and decision.

### **Problem and Purpose Statement**

PrEP initiation decision-making processes are unknown in MSM or any population. Decision-making details what and how individuals consider and evaluate the different factors surrounding a choice or option (Poortaghi et al., 2015; Popejoy, 2005). The purpose of the study is to apply qualitative methods to explore PrEP initiation decision-making processes of HIV-negative MSM engaging in protected or unprotected AI. Qualitative research is necessary when the study's purpose is to understand the meaning of a human experience in the terms and perspectives from the people experiencing the phenomenon (Creswell, 2013; Lo-Biondo &

Haber, 2014). Congruent with qualitative research, this study explores the factors and process that influence this population's decision to initiate PrEP based on what they know and perceive about PrEP and their HIV risk(s)/concern(s).

### **Background**

Despite FDA approval of Truvada as PrEP in 2012, a paucity of literature exists about MSM's PrEP initiation decision-making process. Most research on MSM and PrEP pertain to gauging their interest in initiating this complementary regimen. The literature documents MSM's interest in initiating PrEP to arise for different reasons. MSM perceive PrEP to be a form of proactive prevention (Oldenburg et al., 2016), which is more effective than reactive prevention (i.e., nPEP treatment) (CDC, 2014b; Siemieniuk et al., 2015). Research show that MSM believe PrEP is empowering, as it provides added HIV protection (Brooks et al., 2012; Collins McMahan, & Stekler, 2016; Taylor et al., 2014). Pertaining to MSM's PrEP initiation decision-making, limited data exist. Inquiries about MSM's PrEP initiation either are few in numbers or conducted in the hypothetical context of PrEP (Hoff et al., 2015; Koblin et al., 2011). Currently in the literature, two publications explore some aspect of MSM's PrEP initiation from actual patients; however, these studies only confirm that MSM initiate PrEP to prevent contracting HIV (Garcia & Harris, 2017; Parker et al., 2015), as the processes determining how MSM came to the decision is not known. Given MSM's HIV prevention challenges and PrEP's efficacy, knowledge of MSM's PrEP initiation decision-making processes is necessary to understand this population's most important and valued factors motivating and determining their initiation of this new and effective HIV preventative regimen.

Decision-making to initiate other HIV preventative regimens have been studied in the MSM population, especially condom use. Consistent condom-use is the best defense to HIV

prevention regarding AI (CDC, 2015c, 2016c), and MSM's decision-making processes to utilize condoms has been extensively researched and discovered to be a complex entity. HIV concern, psychosocial issues, and relationship dynamics all are factors in their decisional process to use or not use condoms (Balan et al., 2013; Bauermeister, Carballo-Diequez, Ventuneac, & Dolezal, 2009; Calabrese, Reisen, Zea, Poppen, & Bianchi, 2012; Campbell et al., 2014; Eaton, Kalichman, O'Connell, & Karchner, 2009; Goldenberg, Finneran, Andes, & Stephenson, 2015; Greene, Andrews, Kuper, & Mustanski, 2014; Herrmann, Johnson, & Johnson, 2015; Neville & Adams, 2009; Neville, Adams, Moorley, & Jackson, 2016). Like condom use, PrEP initiation is a preventative behavior, but findings regarding MSM's condom-use decision-making cannot be automatically generalized to PrEP initiation decision-making.

PrEP shares similarities with condom use. Both PrEP and condom-use significantly reduce HIV risk, up to 92% and 72%, respectively, and are personal choices. Additionally, for optimal risk-reduction, both are recommended to be used together and in combination with other traditional HIV prevention practices (Caceres et al., 2015; CFA, 2014; CDC, 2016c, 2014b). Despite these similarities, several variances exist, as accessibility, pharmacotherapeutic risks, drug-resistance, and clinical indications make PrEP significantly different from condom use.

PrEP is not readily accessible in comparison to condoms. Truvada's monthly cost ranges from \$1300 to \$1425 U.S. dollars (USDs), with an estimated annual cost of at least \$10,000 to \$17,000 USDs (Hellinger, 2013; Horberg & Raymond, 2013; Krakower & Mayer, 2015; McMahon et al., 2014; Petroll, Staden, & Westergaard, 2016). Given FDA approval, most third party payers should cover PrEP, and many state Medicaid formularies declare that it will be covered (Krakower & Mayer, 2015). Data also show that private insurances are covering some portion of the cost, but actual insurance coverage percentages and out-of-pocket patient expenses

are presently unknown (McMahon et al., 2014; Rooney, 2013). Due to PrEP's exorbitant cost, patients may receive assistance from Gilead®. Gilead® provides a medication assistance program for qualifying persons with a low socioeconomic status (SES) and inadequate insurance coverage (Horberg & Raymond, 2013; McMahon et al., 2014; Rooney, 2013). Condoms, however, are cheap (Terris-Prestholt & Windmeijer, 2016), costing \$6 to \$12 USDs for a box of three to twelve condoms, respectively (Planned Parenthood, 2017). Due to low cost, condom distribution programs (CDPs) in the U.S. are able to provide condoms free of charge to the public (CDC, 2015b), which is not an option for PrEP.

Compounding PrEP access is the fact that the approved drug, Truvada, is a prescription medication. Consequently, initiating PrEP requires one to access a prescribing provider and to submit to follow-up care at least quarterly (CDC, 2014b); however, there are a limited number of PrEP providers. Studies report that less than 20% of sampled providers in the U.S. have ever prescribed PrEP (Krakower et al., 2015; Tellalian et al., 2013), and 30% of providers who have never prescribed PrEP believe they are unlikely do so in the future (Krakower et al., 2015). Access to a prescribing provider is not apparent with condoms, as they are conveniently available in stores throughout the U.S., detached from any required follow-up care.

Like many medications, Truvada poses pharmacotherapeutic risks. Although typically resolved within the first two weeks of initiation, nausea, headache, and abdominal pain are common side effects of Truvada (CDC, 2014b); however, long-term risks are associated with PrEP. Over a period of taking Truvada, patients can develop nephrotoxicity and bone mineral density loss (CDC, 2014b). These pharmacotherapeutic risks have been reported as reasons that providers are resistant to prescribing PrEP (Blackstock et al., 2016; Hakre et al., 2014; Krakower et al., 2015; Krakower, Ware, Mitty, Maloney, & Mayer, 2014; Tellalian et al., 2013).

Additionally, there is a chance Truvada can cause other unknown side effects, adverse effects, or decrease in efficacy. Another pharmacological aspect to Truvada is the onset of effectiveness. For optimal efficacy, Truvada must be taken daily, but its effectiveness is not immediate (CDC, 2014b). At present, no data exists regarding when HIV protection is achieved in penile tissues, but evidence shows Truvada reaches an optimal HIV prevention level in blood and rectal tissue approximately after seven days of consistent use (CDC, 2014b). Adherence remains the caveat, as continued adherence to the daily regimen is necessary to maintain effectiveness (CDC, 2014b). Condoms do not present patients with pharmacotherapeutic risks, and with proper use, condoms are instantly effective, and only need to be used during sexual encounters.

For PrEP patients who seroconvert, development of Truvada-associated drug resistance is also a possibility (CDC, 2014b; Grant & Liegler, 2015; McCormack et al., 2016). Truvada-associated drug resistance develops because an individual continues to use the drug after becoming infected (acquired drug resistance, ADR) (Dimitrov et al., 2016). Although Truvada is approved for treating HIV, Truvada, an NRTI alone is not an appropriate HIV treatment regimen (AIDS Info, 2017b). Generally, treatment naive PLWH's first regimen includes two NRTIs in conjunction with an integrase strand transfer inhibitor (INSTI), an non-nucleoside reverse transcriptase inhibitor (NNRTI), or a protease inhibitor (PI) with Tybost or Norvir to increase the PI's effectiveness (AIDS Info, 2017b). After contracting HIV, the virus replicates rapidly; viral replications that develop while taking an inadequate HIV regimen cause the virus to mutate into a resistant strain resulting in therapy ineffectiveness and treatment failure (AIDS Info, 2017a). Although PrEP clinical trial data show the development of overall ADR to be low (37 out of 117 seroconverters in the investigational groups developed resistance in six different clinical trials) (CDC, 2014c; Gupta et al., 2013), more research is necessary to assess the relationship between

PrEP seroconversion and ADR (Dimitrov et al., 2016; Grant & Liegler, 2015; Gupta et al., 2013). The implications of PrEP-ADR is another barrier and reason preventing providers from implementing and offering PrEP in their practices (Blackstock et al., 2016; Hakre et al., 2014; Krakower et al., 2015; Krakower et al., 2014; Tellalian et al., 2013), and condoms do not present ADR concerns or threats.

Lastly, depending on one's HIV risk factors, PrEP may not always be clinically indicated. PrEP is recommended for those at increased risk for contracting HIV (CDC, 2014b). An individual's personal behaviors and circumstances can change, making PrEP not always necessary, whereas, condoms and other traditional behaviors are always appropriate for reducing HIV transmissions. Given the differences between PrEP and condom use, an inquiry regarding MSM's decision-making to initiate this new and unique HIV preventative regimen is appropriate and necessary.

### **Research Question**

Based on the knowledge gap and study purpose, the investigator proposes the following research question: How do HIV-negative MSM, engaging in protected or unprotected AI, decide to initiate PrEP? The study objective is to explore how HIV-negative MSM decide to initiate PrEP based on the evaluation and perceptions pertaining to their: (a) PrEP knowledge and HIV risk(s)/concern(s); (b) personal and social motivations to initiate PrEP; and (c) behavioral skills and abilities to adhere to PrEP.

### **Theoretical Framework**

A theory is a set of empirically defined assumptions, concepts, perceptions, and predictions that explain phenomena logically in a particular context or setting (McEwen, 2014). This study explores the PrEP initiation decision-making processes in HIV-negative MSM, and an

appropriate theoretical framework captures decision-making's dynamic process in the context of HIV prevention.

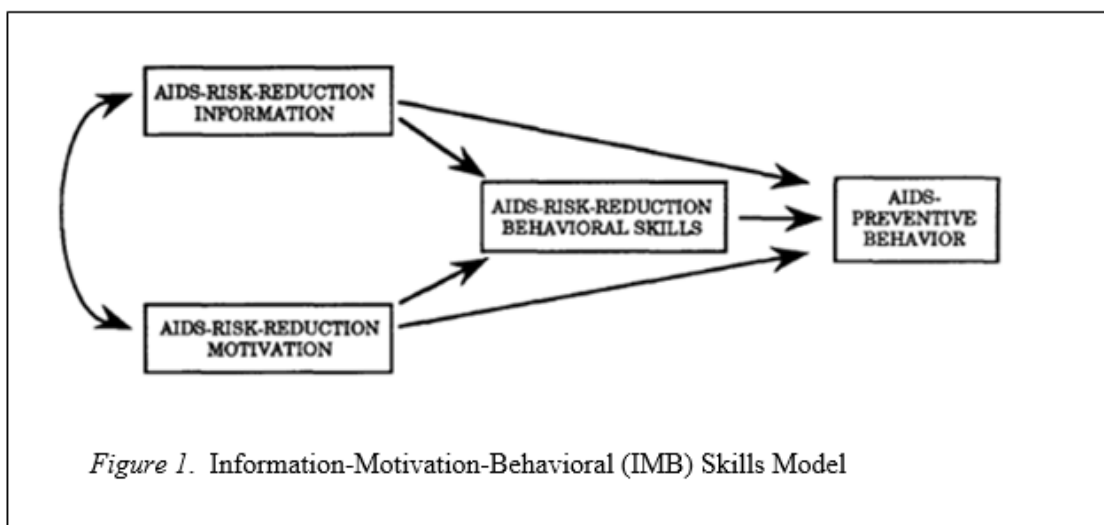
The investigator reviewed HIV/AIDS prevention behavioral literature, and found the Health Belief Model (HBM) and Theory of Planned Behavior (TPB) to be commonly used. These theories have historically guided inquiries including partner condom-use discussions, HIV testing, pregnancy prevention (Li, Lei, Weng, He, & Williams, 2016; Montanaro & Byran, 2014; Schnall, Rojas, & Travers, 2015); PLWH's medication adherence (Jones, Smith, & Llewellyn, 2014); STI testing and treatment adherence; receipt of HIV results; and condom and drug use (Gredig, Nideroest, & Parpan-Blaser, 2006; Mausbach, Semple, Strathdee, & Patterson, 2009; Montanaro & Byran, 2014; Prabawanti, Dijkstra, Riono, & Hartana, 2015; Prati, Mazzoni, & Zani, 2014; Thomas, Shiels, & Gabbay, 2014; Thompson-Leduc, Clayman, Turcotte, & Legare, 2014; Tyson, Covey, & Rosenthal, 2014).

The HBM and TPB both explain and represent some aspect regarding health behavioral decision-making; however, these models do not fit this inquiry's clinical context. Developed in the 1950s and 1960s by social psychologists Hochbaum, Rosenstock, and Kegels, the HBM is a cognitive model to explain and predict the likelihood or intention of performing health behaviors (Jones et al., 2014; Li et al., 2016; Montanaro & Byran, 2014; Schnall et al., 2015). In this study, intention to initiate PrEP is not the investigated phenomenon, as participants have already initiated PrEP, therefore, deeming the HBM's to be inappropriate to guide this study. The TPB originated from the psychology discipline by Ajzen to predict health behaviors based upon one's personal perceptions (Ajzen, 2002, 2011; Madden, Ellen, & Ajzen, 1992). The TPB is not a befitting theory for this investigation, because it conceptualizes decision-making to be based on the personal perceptions about the behavior alone, but this inquiry's context includes PrEP



initiation based upon multiple factors: (a) PrEP knowledge and HIV concern(s)/risk(s); (b) personal and social motivations to initiate PrEP; and (c) behavioral skills and abilities to adhere to PrEP. Since neither model represents the clinical context of the proposed study, the investigator chose a different framework that better attests to this study's context.

The Information-Motivation-Behavioral (IMB) skills model is the theoretical framework guiding this exploration into MSM's PrEP initiation decision-making processes. The IMB skills model is rooted in and specific to AIDS preventative and treatment behaviors (Aliabadi et al., 2015; Chang, Choi, Kim, & Song, 2014; Fisher & Fisher 1992; L. Smith, Fisher, Cunningham, & Amico, 2012). Originating from the psychology discipline, Fisher and Fisher (1992) conducted a comprehensive review of AIDS-related risk-reduction literature. From their empirical synthesis and analysis, they constructed the IMB skills model (see Figure 1) to explain one's process for initiating AIDS risk-reduction behaviors (Aliabadi et al., 2015; Chang et al., 2014; Fisher & Fisher 1992; L. Smith et al., 2012; Traube, Holloway, & Smith, 2011). For clarity, the investigator refers to the model's purpose to explain the phenomenon of an individual initiating HIV risk-reduction behaviors, as HIV is the virus that causes AIDS, and HIV prevention is necessary to reduce HIV/AIDS incidence (CDC, 2016c; Fan et al., 2014).



The IMB skills model conceptualizes the decision to initiate HIV risk-reduction behaviors as involving one's information, motivation, and skills (Aliabadi et al., 2015; Amico, Toro-Alfonso, & Fisher, 2005; Amico et al., 2009; Chang et al., 2014; Fisher & Fisher, 1992; Macapagal, Greene, Andrews, & Mustanski, 2016; L. Smith et al., 2012). Information is the initial prerequisite to health behavior, as it is the knowledge, myths, and means known to reduce the risk of contracting HIV (Aliabadi et al., 2015; Amico et al., 2005; Amico et al., 2009; Chang et al., 2014; Fisher & Fisher, 1992; Macapagal et al., 2016). Motivation encompasses two types, personal and social. Personal motivations are one's attitudes, beliefs, and perceptions regarding the outcomes from performing or not performing HIV prevention behaviors (Aliabadi et al., 2015; Amico et al., 2005; Amico et al., 2009; Chang et al., 2014; Fisher & Fisher, 1992; Macapagal et al., 2016). Social motivations are the perceived social support and acceptance from peers and significant others in performing the specific behavior (Aliabadi et al., 2015; Amico et al., 2005; Amico et al., 2009; Chang et al., 2014; Fisher & Fisher, 1992; Macapagal et al., 2016). Behavioral skills are the abilities needed to perform that behavior, and are a reflection of one's knowledge and motivation (Chang et al., 2014; Traube et al., 2011). Engagement in a behavior requires one to possess and utilize certain skills to achieve and perform the behavior (Aliabadi et al., 2015; Amico et al., 2005; Amico et al., 2009; Chang et al., 2014; Fisher & Fisher, 1992; Macapagal et al., 2016). In regards to MSM HIV prevention, those skills include having condoms readily available and accessible, using condoms accurately and consistently, reducing sexual partners, and avoiding sex while cognitively impaired (Herbst et al., 2007; Motley, Hammond, & Mustanski, 2017; Sullivan et al., 2012). While the model's three concepts individually influence HIV prevention behaviors, the combination of all three concepts shows the decision-making process for initiating HIV preventative behaviors (Aliabadi et al., 2015; L.

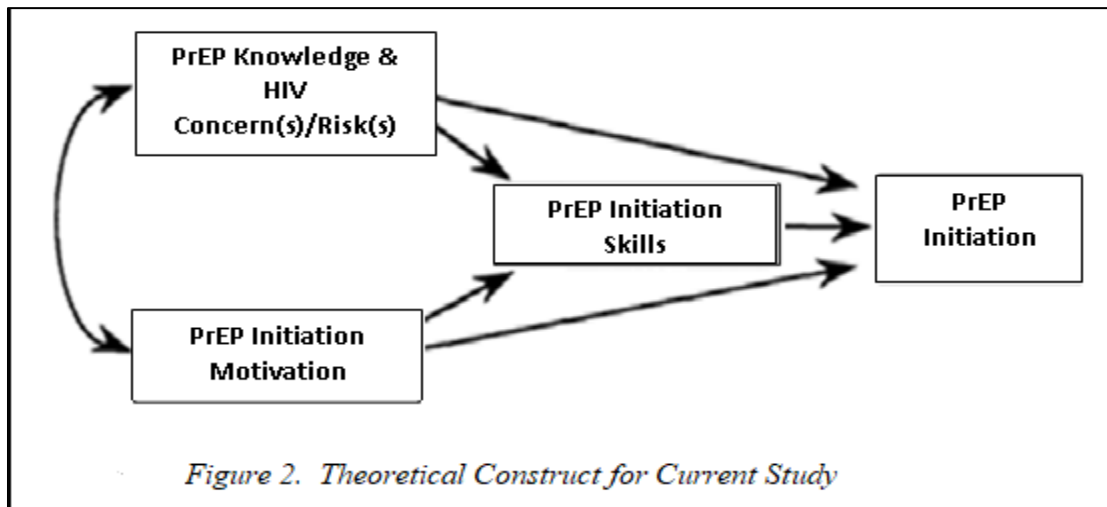
Smith et al., 2012). The information and motivation one has regarding HIV risk-reduction behaviors directly influence their skills and abilities to perform and adhere to the behavior (Fisher & Fisher, 1992). In this model, however, information and motivation are unique constructs, meaning that these concepts do not directly influence the other (Chang et al., 2014; Fisher & Fisher, 1992). A highly motivated person can lack adequate knowledge, while a well-informed person can have little to no motivation (Traube et al., 2011).

As a whole, the three concepts influence initiation of HIV prevention behaviors, but the concepts are context and value-dependent (Aliabadi et al., 2015; Chang et al., 2014; Fisher & Fisher, 1992; L. Smith et al., 2012). Under this framework, an individual's culture, values and beliefs, social standing, SES, environment, and life circumstances determines their understanding, motivation, and abilities regarding their decision-making to utilize HIV preventative behaviors (Aliabadi et al., 2015; L. Smith et al., 2012; Traube et al., 2011). Therefore, Fisher and Fisher (1992) recommend conducting HIV prevention research among a subsample of a population in order to prevent making overzealous generalizations (Aliabadi et al., 2015). Additionally, Aliabadi et al. (2015) stated that a qualitative approach is appropriate with the IMB skills model so information can be elicited using dialogue and open-ended questions.

Although not as commonly used in HIV research as the HBM and TPB, investigators have applied the IMB skills model to investigate different behaviors related to HIV prevention. These investigated HIV behaviors include risky sexual behaviors in HIV positive and negative persons (Chang et al., 2014; Macapagal et al., 2016), PLWH medication adherence (Aliabadi et al., 2015; Chang et al., 2014; Horvath, Smolenski, & Amico, 2014; Rongkavilit et al., 2010), and intervention development and testing (Chang et al., 2014). The IMB skills model has also been

applied in exploring health-related behavioral initiation in other diseases and diagnoses: coronary artery disease (Zarnai, Besharat, Sarami, & Sadeghian, 2012), Type 2 diabetes mellitus (Gavvani, Poursharifi, & Aliasgarzadeh, 2010; Meunier et al., 2016; Osborn et al. 2010), and cervical or endometrial cancers (Jefferies, Robinson, Craighead, & Keats, 2006). As the newest and first pharmacological HIV prevention intervention, PrEP, inquiries into initiating this regimen can be conducted utilizing this framework.

The proposed study explores MSM's decision-making processes to initiate PrEP based on their (a) PrEP knowledge and HIV concern(s)/risk(s); (b) personal and social motivations to initiate PrEP; and (c) behavioral skills and abilities to PrEP adherence. This investigator believes the IMB skills model provides the most congruent context given the complexity surrounding HIV behavioral prevention initiation. Figure 2 displays the theoretical construct specific to this study.



### Assumptions

Assumptions for this inquiry are based on the presumption that individuals institute prevention behaviors due to a health concern or scare (Poortaghi et al., 2015), and that qualitative research seeks to understand human experiences from participants' personal experiences

(Creswell, 2013; Lo-Biondo & Haber, 2014). Therefore, specific to this inquiry, the investigator assumes MSM PrEP patients: (a) acknowledge they are at risk for HIV; (b) are concerned about contracting HIV; (c) do not want to contract HIV; (d) believe PrEP initiation decreases their HIV risk(s); (e) are the experts of this phenomenon; and (f) tell the truth as they see it. The investigator also assumes health decision-making to be a personal and individualistic process of considering, weighing, and rationalizing the benefits and consequences perceived by initiating or not initiating health related behavior(s).

### **Definition of Terms**

Defining key terms is imperative to provide phenomenal clarity throughout the investigation.

**Health professionals** are licensed nurses, physicians, and mid-level practitioners providing medical services and care to patients.

**HIV** is the virus that causes AIDS, which is transmitted through blood, breast milk, semen, and vaginal fluids.

**MSM** are men who engage in sex with other men.

**PrEP or Truvada as PrEP** is the fixed daily oral-dose of Truvada in HIV-negative persons.

**PrEP initiation** is the act of a person beginning to take PrEP.

**Decision-making process** is the individual process of weighing different factors, as understood by the individual, surrounding that behavior or choice's requirements, benefits, and outcomes, prior to one taking action or inaction regarding that particular behavior or choice (Poortaghi et al., 2015; Popejoy, 2005).

### **Limitations**

Limitations are weaknesses in a study, restricting the application and relevance of its findings in clinical practice (Colorafi & Evans, 2016; LoBiondo-Wood, 2014b; Neergaard, Olesen, Andersen, & Sondergaard, 2009). In this study, limitations relate to the proposed study's research question, methodology, and implications.

Inquiring about MSM's PrEP initiation decision-making process makes this investigation privy to respondent bias. Respondent bias occurs when participants are less than honest, answering research questions according to social norms and acceptance; relevant research data depend on participants' responses being authentic and truthful (Friis & Sellers, 2013). Although PrEP is initiated in HIV-negative persons, HIV and PrEP are sensitive topics, as fears and concerns of stigmatization remain among patients seeking HIV care and prevention services (CDC, 2016b). Given that PrEP is clinically indicated for those at high HIV risk, PrEP users have been labeled "Truvada whores", and the negative stigma prevents patients from seeking and initiating PrEP (Auerbach, Kinsky, Brown, & Charles, 2015; Calabrese & Underhill, 2015; Collins et al., 2016; Dolezal et al., 2015; Haire, 2015). Likewise, the negative stigma might deter participants from being honest about their PrEP initiation decision-making process. Patients are shown to have reservations when discussing sexual health matters with health professionals. Suspicions and experiences of medical judgment and mistrust prevent patients from discussing their sexual behaviors (Auerbach et al., 2015; Collins et al., 2016; Eaton et al., 2014; Garcia & Harris, 2017; Perez-Figueroa, Kapadia, Barton, Eddy, & Halkitis, 2015; Taylor et al., 2014). These reservations can extend into this study, as participants may not be as open and honest with discussing their HIV risks and concerns, or motivations for initiating PrEP. Gender differences can also influence respondent bias, as participants may not be as forthcoming and honest in their responses with a female interviewer.

Utilizing a qualitative methodology causes this study to be limited by interviewer bias (Sullivan-Bolyai & Bova, 2014). Interviewer bias, implicit or explicit, occurs when the interviewer leads the participant to answer in a certain manner (Sullivan-Bolyai & Bova, 2014), distorting the emic view. The emic view is the actual view and perspective of the person experiencing the phenomenon (Streubert, 2014). The researcher's professional experience with HIV and PrEP patients can cause the investigator, intentionally or not, to lead participants' responses during interviews. While the investigator is experienced in clinical research, she is a novice investigator, inexperienced in conducting and analyzing qualitative research. During data collection and analysis, inexperience and interviewer bias makes this process at risk to misinterpretations, threatening the authenticity of study findings.

Study implications are also limited in this study, as these findings are not transferable to the larger MSM PrEP population. Usually, a rigorous study is transferable to the larger population of the study sample (Colorafi & Evans, 2016; Creswell, 2013; LoBiondo-Wood, 2014b; Neergaard et al., 2009); however, those studies are generally replications of previous or similar studies (Houghton, Casey, Shaw, & Murphy, 2013). Prior to this investigation, there are no publications exploring MSM's PrEP initiation decision-making processes. Given the lack of knowledge on MSM's PrEP initiation decision-making processes, it is premature to assert that these initial findings are applicable to other MSM PrEP patients. Additionally, qualitative research is based on a philosophical foundation that "reality is socially constructed and context dependent" (Toles & Barroso, 2014b, p. 96). Therefore, these findings are transferable to this sample, and possibly to MSM of similar social demographics who are accessing PrEP. Future replicated studies are needed before making generalizations regarding MSM's PrEP initiation decision-making in the U.S.

### **Significance to Healthcare & Nursing**

Health behavior decision-making has been studied in numerous specialties and areas: exercise (Lee, Chiang, Hwang, Chi, & Lin, 2016), hormone replacement therapy (Carpenter, Studts, & Bryne, 2011), medication adherence (McGrady, Brown, & Pai, 2016), healthy eating (Haws, Reczek, & Sample, 2017), smoking cessation (Hoie, Moan, Rise, & Larsen, 2012), self-care (Karimi & Clark, 2016), and sexual behaviors (Scott-Sheldon et al., 2016). The consensus is that decision-making is an individualistic process where the decision-maker weighs different factors, as they understand them, surrounding that choice's requirements, benefits, and outcomes (Poortaghi et al., 2015; Popejoy, 2005). Exploring MSM's PrEP initiation decision-making processes informs health professionals of MSM's (a) knowledge and values about PrEP, (b) HIV risks and concerns; and (c) perceptions and abilities surrounding PrEP initiation and adherence.

Knowledge from this study has cost saving implications for the U.S. health-care system. HIV care and treatment costs the health-care system an estimated \$12.3 billion annually (CDC, 2015a). Each prevented HIV infection saves an estimated \$355,000 in lifetime HIV treatment costs (CDC, 2015a). Experts estimate that PrEP initiation in at-risk groups can reduce HIV incidence by 70%, preventing 185,000 U.S. infections by 2020 (CDC, 2016e), but the capacity to achieve the projected decline depends on PrEP indicated persons deciding to initiate the complementary regimen. Although this study will not lead to an increase in PrEP initiation, the findings are informative, providing context and information surrounding MSM's PrEP initiation in the U.S. MSM is the population most affected and vulnerable to HIV, and given the poor PrEP initiation in this population (Krakower et al., 2015; Krakower & Mayer, 2015; Tellalian et al., 2013), knowledge of HIV-negative MSM's PrEP initiation decision-making processes is a



step to gauge if the complementary regimen can have the estimated impact to change the narrative surrounding the current U.S. HIV epidemic and MSM disparity.

Knowledge of MSM's PrEP initiation decision-making processes implicates the nursing profession. Nurses advocate, support, and educate patients on health-promoting options to help patients achieve the best outcomes they perceive for themselves (Kemppainen, Tossavainen, & Turunen, 2012; Kim, 2015). The findings inform nurses of how MSM process and rationalize these factors when deciding to initiate PrEP. With greater understanding of the knowledge and factors influencing and determining PrEP initiation decision-making, nurses are able to identify opportunities to assist patients in resolving occurrences of internal and external conflict, misunderstanding, or other concerns regarding HIV and PrEP.

Empirical evidence of MSM's PrEP decision-making processes informs nurses of possible content to include when providing PrEP patient education to MSM. This study's findings educate nurses on ways to counsel and support MSM considering PrEP. A greater feeling of support and advocacy increases health behavioral adherence (Popejoy, 2005; Thom et al., 2016), and optimal and accurate PrEP initiation among willing and HIV at-risk persons is the most effective way for PrEP initiation to have the projected impact on the HIV epidemic (CDC, 2016e).

Findings from this study are foundational, extending the current knowledge base encompassing MSM's PrEP initiation decision-making. Additionally, findings from this study build on previous evidence pertaining to health behavioral decision-making, HIV prevention, and PrEP and MSM decision-making. PrEP initiation is a new phenomenon, and this study's findings establish a knowledge base for conducting future inquiries into PrEP initiation. Qualitative explorations such as this inquiry are indicated and useful in contributing to the

development of evidenced-based instruments and tools (Toles & Barroso, 2014b). Evidenced-based practice is applying and instituting clinical standards and interventions based on empirical evidence (Lo-Biondo & Haber, 2014). Specific to MSM's PrEP initiation decision-making, decision aids and decisional coaching are possible interventions, which can be developed from inquiries such as this. Decision aids assist nurses to counsel and coach patients when debating between different options (Stacey et al., 2008), as it is a complementary, pamphlet, form, web page, or video “that helps patients make decisions by (a) providing information about the available options and outcomes and (b) clarifying their personal values” (Eggertson, 2010, p. 39). Decision coaching is another avenue in which nurses educate and support patients in choosing the best health-care plan and intervention (Stacey et al., 2008; Thom et al., 2016). For accuracy and relevancy, best practices recommend the targeted population to be involved in the development of population-specific interventions (Dugas et al., 2017). Therefore, this study contributes to future development and testing of MSM PrEP initiation decision tools and interventions, which can lead to devising and implementing evidenced based resources and strategies for achieving PrEP initiation success.

### **Summary**

The MSM HIV epidemic continues to thrive in the U.S., as MSM account for majority of current and past HIV/AIDS diagnoses. MSM's HIV incidence rate is 44 times higher than in other men and 40 times higher than in women (CDC, 2016d). At this rate, the CDC (2016c) estimates that 1 in 6 MSM will contract the virus in their lifetime. AI is MSM's greatest risk factor for contracting and transmitting HIV, as it is the overall most common mode of HIV transmission (CDC, 2016d), and the riskiest type of sex (CFA, 2014; Pebody, 2010). HIV prevention is the key to decreasing MSM's current and predicted HIV incidence in the U.S.

(CDC, 2016c; Fan et al., 2014). Although HIV prevention behavioral interventions provide best practices to increasing MSM's implementation of HIV risk-reduction behaviors (CDC, 2015a, 2017a), the HIV incidence shows that prevention challenges persist. Therefore, a new HIV prevention modality, PrEP, was introduced as the first pharmacological agent.

PrEP is the fixed daily dose of Truvada in HIV-negative persons with reported and documented high HIV-acquisition risk (CDC, 2014b). Clinical trial data showed that in the event of an exposure, PrEP reduces HIV seroconversion by as much as 92%; however, adherence to the daily regimen is necessary to achieve optimal efficacy (CDC, 2014b; Koenig et al., 2013). Although efficacious, PrEP does not provide 100% HIV protection and is complementary, recommended to be used in conjunction with other traditional HIV risk-reduction behaviors, especially consistent condom usage (CDC, 2014b). Despite PrEP's indications and efficaciousness, initiating PrEP is an individual choice and decision. Most current and former PrEP patients are MSM (Krakower et al., 2015; Krakower & Mayer, 2015; Tellalian et al., 2013), but currently there is no research exploring PrEP initiation decision-making processes in MSM or any population.

This study's purpose is to explore PrEP initiation decision-making processes of HIV-negative MSM engaging in protected or unprotected AI. Decision-making details what and how individuals consider and evaluate the different factors surrounding a choice or option (Poortaghi et al., 2015; Popejoy, 2005). The study objective is to explore how HIV-negative MSM decide to initiate PrEP based on the evaluation and perceptions pertaining to their: (a) PrEP knowledge and HIV concern(s)/risk(s); (b) personal and social motivations to initiate PrEP; and (c) behavioral skills and abilities to adhere to PrEP. The IMB skills model guides this inquiry, as it is consistent with this study's objective and the conceptualization of health-behavioral and HIV

decision-making. Under this framework, the decision to initiate HIV risk-reduction behaviors includes one's knowledge, motivation, and skills regarding the preventative behavior (Aliabadi et al., 2015; Amico et al., 2005; Amico et al., 2009; Chang et al., 2014; Fisher & Fisher, 1992; Macapagal et al., 2016; L. Smith et al., 2012).

Knowledge from this study implicates the health-care system and nursing profession. Although this study will not lead to increasing PrEP initiation in the U.S., the findings are informative. Experts estimate that PrEP initiation in at-risk groups can reduce HIV incidence by 70%, and prevent 185,000 U.S. infections by 2020 (CDC, 2016e). Each prevented HIV infection saves an estimated \$355,000 in lifetime HIV treatment (CDC, 2015a). Knowledge from this study is a step to gauge if this complementary regimen can have the estimated impact on the HIV epidemic, and change the current MSM HIV disparity. MSM's PrEP initiation decision-making process informs nursing practice of factors that influence PrEP decision-making and how MSM rationalize initiating PrEP based on their HIV and PrEP perceptions and understanding. With this knowledge, nurses are able to identify opportunities to assist patients during the decision-making process, clarifying HIV and PrEP misunderstandings and misconceptions. Therefore, this study's findings educate nurses on ways to counsel and support MSM considering PrEP. Additionally, this study contributes to the future development and testing of MSM PrEP initiation decision tools and interventions, which can lead to devising and implementing evidenced based strategies for achieving PrEP initiation success.

Despite the study's implications, this study is still privy to limitations. Inquiring about MSM's PrEP initiation decision-making process requires the investigator to ask about behaviors and perceptions related to HIV, sex, and PrEP. PrEP users are negatively stigmatized as "Truvada whores" (Calabrese & Underhill, 2015; Haire, 2015), and some patients fear discussing

their sexual behaviors with health professionals (Auerbach et al., 2015; Collins et al., 2016; Eaton et al., 2014; Garcia & Harris, 2017; Perez-Figueroa et al., 2015; Taylor et al., 2014). These fears and concerns make this study at risk for respondent bias, as participants may be less than truthful with their responses (Friis & Sellers, 2013). A qualitative methodology and the investigator's professional background also make this study limited by interviewer bias, which can distort the emic view due to data collection errors or misinterpretation. Lastly, as the first known investigation into MSM's PrEP initiation decision-making processes, transferability is limited. Rigorous studies are usually transferable to the study sample's larger population (Colorafi & Evans, 2016; Creswell, 2013; LoBiondo-Wood, 2014b; Neergaard et al., 2009); however, these findings are only transferable to this sample, and possibly to MSM of similar social demographics and accessibility means to PrEP.

## Chapter 2: Literature Review

In July 2012, pre-exposure prophylaxis (PrEP) was introduced as HIV prevention's inaugural pharmacological agent for individuals at increased HIV risk. As PrEP, HIV-negative patients take Truvada, an antiretroviral therapy (ART) drug, once a day to decrease HIV risk by as much as 92% (CDC, 2014b). PrEP is complementary, as it is to be used in conjunction with other traditional HIV risk-reduction behaviors, and strict adherence is required to achieve optimal efficacy (CDC, 2014b). Despite these limitations, the introduction of Truvada as PrEP has the potential to end the HIV epidemic in the U.S., as PrEP initiation in HIV at-risk populations is predicted to result in a 70% reduction in HIV incidence in the U.S. by 2020 (CDC, 2016e). Although HIV risk is significant in other populations, men who have sex with men (MSM) are most vulnerable, experiencing the highest HIV incidence and prevalence annually and historically. MSM represent 56% of people living with HIV (PLWH), and account for more than half of the new cases each year in the U.S. (CDC, 2018a). The MSM HIV epidemic is so alarming that CDC (2016c) estimates that 1 in 6 MSM will contract the virus in their lifetime if this rate continues, making PrEP initiation HIV-negative MSM significant to the U.S. MSM HIV epidemic.

Research shows that MSM are interested in initiating PrEP (Brooks et al., 2012; Collins et al., 2016; Taylor et al., 2014), because they perceive it to be an empowering form of HIV proactive prevention (Oldenburg et al., 2016). Although most current and former PrEP patients identify as MSM (Krakower et al., 2015; Rooney, 2013; Tellalian et al., 2013), approximately 3% of the MSM population have ever initiated the complementary regimen (Krakower et al., 2015; Krakower & Mayer, 2015; Tellalian et al., 2013). At present, the literature lacks evidence of PrEP initiation decision-making processes in any population and this study attempts to address

this knowledge gap by exploring PrEP initiation decision-making processes in the most HIV-vulnerable population, HIV-negative MSM.

In order to understand this study's implications, a literature review was conducted to establish the foundation for the proposed study. A literature review functions as the knowledge base on a phenomenon by gathering and appraising current and relevant evidence (Fulton & Krainovich-Miller, 2014). PrEP is an HIV preventative regimen, and this chapter provides the literary foundation for an inquiry into this exploration into MSM's decision-making to initiate this regimen. First, the investigator discusses recommendations and best practices for MSM behavioral HIV prevention. Second, the significance health-behavioral decision-making research has in clinical practice are revealed. Thirdly, the synthesis details the factors and processes involved in HIV-negative MSM's condom-use decision-making. Finally, the results of this literature review determines the current knowledge base on MSM and PrEP. The chapter concludes with a summary validating the need for the proposed study based on the literature's current knowledge gap.

### **HIV Prevention**

Since the beginning of the epidemic, HIV incidence shows that "HIV prevention is neither simple nor simplistic" (Coates, Richter, & Caceres, 2008, p. 669). In the initial onset, HIV prevention was a challenge due to the lack of knowledge and understanding about HIV's etiology and disease progression. Over the past three decades, HIV science and research have discovered the virus' transmission modes, therefore, allowing successful development of best practice prevention strategies. Although the national HIV incidence has declined by 19% between 2005 and 2014, prevention challenges remain, as approximately fifty thousand new HIV cases are reported annually in the U.S. (CDC, 2016c). Due to these continued challenges, HIV

prevention has expanded into a three-tiered approach: behavioral interventions, routine testing, and treatment as prevention (TasP) (CDC, 2015a; Yagoda & Moore, 2016).

Undiagnosed infections fuel the HIV epidemic, as these cases allow the virus to spread unknowingly (CDC, 2016b). To eliminate missed opportunities for early diagnosis, the CDC (2006, 2012) currently recommends routine testing, which advises health professionals to conduct HIV testing on all patients 13-65 years of age during all health care encounters regardless of clinical indications or reported risks. Patients meeting the age criteria with an HIV-negative or unknown status should be offered an HIV test each and every time they present for any medical services, but patients maintain the right to decline, or “opt-out” of the service (CDC, 2006, 2012). Routine testing’s goal is to identify new and unknown cases sooner and more frequently by making it an aspect of routine care (CDC, 2012). Once diagnosed, treatment naïve PLWH can be connected to care to begin ART.

Connection to care or, TasP, involves PLWH receiving consistent and adequate ART. ART decreases the viral load in the body to a low or undetectable level, which decreases HIV transmission risk by at least 90% (CDC, 2016f; CFA, 2015; O’Byrne & MacPherson, 2016; Young & McDaid, 2014). PLWH not on ART strains prevention, as the virus remains unstable in their body and readily transmissible. Both routine testing and TasP play a significant role in HIV prevention; however, this study pertains to PrEP initiation, which is the newest option in HIV prevention behavioral interventions.

### **MSM’s HIV Prevention Behavioral Best Practices**

Behavioral interventions encourage individuals to utilize risk-reduction behaviors by “ensuring people have the information, motivation, and skills necessary to reduce their risk” (CDC, 2015a, p. 1). Although behavioral interventions are specifically devised for several at-



risk populations, only those interventions targeting HIV-negative MSM are relevant to this literature review. Anal intercourse (AI) is the most common mode of HIV transmission (CDC, 2016d), the riskiest type of sex (CFA, 2014; Pebody, 2010), and the most common sexual behavior practiced by MSM (Meng et al., 2015). Therefore, most MSM HIV prevention behavioral interventions target reducing HIV risk during AI. Specific to AI for MSM, traditional risk-reduction behavioral interventions include abstaining, using condoms consistently, decreasing sexual partners, serosorting, avoiding sex cognitively impaired, and submitting to substance abuse treatment (CDC, 2017a). A combination of these traditional behaviors is recommended for optimal HIV protection (Caceres et al., 2015; CFA, 2014), but the CDC (2016a) affirms that correct and consistent condom use is the best defense to prevent the spread of HIV during sexual encounters. Protected AI reduces HIV risk by 63% for the insertive partner and 72% for the receptive partner (CDC, 2015c), and serosorting provides an estimated 54% in risk reduction (CDC, 2015c). Although no statistics are available, the logic behind decreasing sexual partners is that this action lessens one's exposure to an individual with a known or unknown HIV positive status (CDC, 2017d). Additionally, engaging in sexual acts while under the influence of drugs or alcohol decreases one's inhibitions and cognitive ability to avoid risky sexual encounters and behaviors (CDC, 2017d). Therefore, avoidance of sex while cognitively impaired and substance abuse treatment reduces opportunities for HIV risky encounters (CDC, 2017d). Behavioral interventions provide HIV prevention education and support at individual, group, and community levels with the shared goal of increasing at-risk individual's utilization of HIV preventative behaviors (CDC, 2014a, 2017a, 2017c); however, each level's intervention is distinct and implemented differently.

Specific to HIV prevention, individual interventions are strategies provided in an intimate setting on a one-on-one basis (CDC, 2014a, 2017a, 2017c), while group interventions are rendered amongst a group of homogenous persons (Herbst et al., 2007). Both individual and group interventions' effectiveness are determined by individual participants' responses to treatment (CDC, 2014a, 2017a, 2017c). Although either of these intervention types can be provided in health care facilities/specialties or other group organizations, they are often conducted and administered at an HIV clinic or health care entity/institution (CDC, 2014a, 2017a, 2017c).

Unlike HIV prevention's individual and group interventions, community interventions bring the intervention directly to the population (CDC, 2014a, 2017a, 2017c). In this type of research, community is defined as a group of individuals sharing common traits and characteristics in a relative close geographic region prior to initiating the intervention (CDC, 2017c). MSM community interventions take place in settings frequented by MSM: gay bars, community based organizations (CBOs), and other social and public areas (i.e., outpatient or community clinics, community colleges, and gay pride events) (CDC, 2017a). The effectiveness of community interventions is measured according to the response from the entire studied community, and not on an individual basis (CDC, 2014a, 2017a, 2017c).

To identify HIV prevention behavioral interventional best practices, the investigator reviewed the CDC's HIV Evidenced Based Interventions (EBIs). Determining evidenced-based interventions is a systematic process of analyzing and evaluating relevant and related research based on data and outcomes (Lo-Biondo & Haber, 2014). The result of the literature analysis and synthesis assists in defining best practice recommendations, protocols, or standards based on objective and sound evidence (Lo-Biondo & Haber, 2014). The CDC's EBIs is a compendium

from their analysis of published HIV behavioral interventional evidence shown to increase initiation of HIV traditional risk-reduction behaviors at the individual, group, and community levels (CDC, 2014a, 2017c). For MSM, the following were considered traditional prevention behaviors: abstinence, decreasing the number of sexual partners, and decreasing the occurrence of unprotected sex (CDC, 2014a, 2017c). Appendix A provides a list of the eleven identified EBIs for MSM at the individual, group, and community levels.

### **Evidenced Based Interventions (EBIs)**

Relative to individual and group interventions, counseling strategies utilizing technology, peers, and health professionals are shown to be most effective (CDC, 2017a). Although these approaches are facilitated differently, the commonalities remain the same and are imperative to their successes. Regardless of whether information is delivered by a video or virtual component, an MSM peer, or a health professional, information is culturally adapted to provide behavioral risk-reduction education, recommendations, and support specific to MSM of different races and ethnicities (CDC, 2017a). After receiving HIV counseling, participants engage in discussions within their group or individual sessions to clarify and expound upon the presented information (CDC, 2017a). Counseling strategies utilizing MSM peer counselors provide opportunities to discuss social barriers, hardships, decision-making, and problem solving (CDC, 2017a). Trained counselors and health professionals are not MSM's peers, but they are equipped and capable to have candid conversations in a safe, non-judgmental environment, as they support and assist clients to devise risk-reduction goals and strategies (CDC, 2017a).

Although not considered best practices, community interventions are shown to be effective and good strategies in improving MSM's HIV risk-reduction behaviors. Community interventions utilize peers and community leaders respected and trusted by MSM to render risk-

reduction counseling (CDC, 2017a). Similar to individual interventions, community interventions empower MSM to develop risk-reduction goals, plans, and skills (CDC, 2017a). At the community level, HIV prevention is an ongoing collaborative effort, as these interventions are provided within the community as an attempt to provide preventative services to those who may not be able to access individual and group level interventions due to personal and disadvantaged circumstances: limited finances, unreliable transportation, and/or inadequate health care access, to name a few.

The CDC conducted a comprehensive and exhaustive review of several literature databases to identify and evaluate applicable studies meeting defined research criteria (CDC, 2014a, 2017c). Although complete details of this evaluation process were not available, the CDC (2014a, 2017c) analyzed each study rigorously according to specific criteria to determine which interventions demonstrated optimal evidence to increase the studied sample's HIV risk-reduction behaviors (CDC, 2017c). Reviewed interventional studies had to meet and demonstrate certain risk-reduction efficacy standards set by the CDC's Prevention Research Synthesis (PRS) Project (CDC, 2017c). The pre-defined evaluation criterion for reviewing the interventional studies strengthens the EBIs' evidence, as setting the required criteria first standardizes and reduces bias in the evaluation process (LoBiondo-Wood, 2014a).

The criteria measuring the interventions' efficacy was determined by evaluating a combination of the intervention's study design and reported outcomes (CDC, 2017c). PRS Project's standards placed more value on a study being a randomized clinical trial (RCT), having a large sample size, maintaining a high retention rate, and utilizing multiple comparison groups (CDC, 2017c). Additionally, included studies reported a statistically significant ( $p < .05$ ) increase in one or more of the HIV traditional prevention behaviors in comparison to the control group

(CDC, 2017c). These characteristics are indicators of a robust study, increasing the findings' reliability and trustworthiness (LoBiondo-Wood, 2014a). From the analysis, the interventions were classified as either best or good practice (CDC, 2014a, 2017c).

The distinction between good and best practice was based upon the overall quality of the study's design and methodology (CDC, 2017c). Individual and group interventions were evaluated utilizing the same criteria (CDC, 2017c); this investigator assumes that was done because both interventions evaluate behavioral change in the individual. For individual and group level interventions, best practices were derived from RCTs utilizing a sample greater than 50 participants per study arm, with a 70% retention rate, and a follow-up period of at least three months post intervention completion (CDC, 2017c). On the other hand, good evidence for individual and group interventional studies utilized random assignment of 40 participants per study arm, with a 60% retention rate, and a follow-up period of at least thirty days post intervention completion (CDC, 2017c). A similar pattern was apparent in the distinction between best and good practices for community interventional research. Best practice community interventional studies utilized four or more communities per study arm, maintained a 70% retention rate, and had a follow-up period of at least three months post intervention completion (CDC, 2017c). Good practice community interventional studies had at least one or more communities per arm, a 60% retention rate, and a follow-up period of thirty days post intervention completion (CDC, 2017c).

Although not an aspect of the PRS Project's evaluation criteria, each reviewed study utilized a theoretical framework to guide the investigation. Appendix B provides a list of the applied theories. Applied theory strengthens the EBIs' conclusions, as developing effective and efficient knowledge for clinical practice depends "on marshaling the most appropriate theory to

guide inquiries that contextually represent the investigated phenomenon” (Glanz et al., 2008b, p. 35). Systematic reviews show interventions constructed from a theoretical framework are more effective compared to interventions not founded on theory (Glanz, Rimer, & Viswanath, 2008a). One benefit of theory application in research is that it allows researchers and health professionals to understand the context and practice settings in which the study findings are most applicable (McEwen, 2014). All interventions are not universally feasible, and should be selected strategically and systematically based upon characteristics and resources of the population and community being served (Collins & Sapiano, 2016). Therefore, theory allows health professionals to better identify the best strategies to implement given their clinical practice settings and populations.

### **Evidenced Based Interventions (EBIs) Synthesis**

Synthesis of the CDC’s compendium implicates the proposed study’s significance to the nursing profession. The applied theoretical frameworks assume that health behavior interventions at different levels are necessary to support individuals and populations being able to initiate and sustain effective behavioral change (Glanz et al., 2008a). Therefore, the compendium demonstrates that health professionals are integral to increasing MSM’s use of risk-reduction behaviors, as MSM need support and guidance from a professional, trusted resource, or program knowledgeable in HIV prevention in order to increase utilization of HIV risk-reduction behaviors (CDC, 2017a, 2017c). Additionally, this evidence shows that MSM are receptive to counseling and education from health professionals in an environment and manner that acknowledges their specific needs and perspectives respectfully and without judgment. Therefore, findings from an exploration of MSM's PrEP initiation decision-making processes inform and educate nurses on the ways and content necessary to counsel and support this

population during this decision-making process. This study is foundational to devising best practices for MSM's PrEP initiation successes, and contributes to the development of future evidenced-based PrEP initiation interventions.

The EBIs' evidence is still privy to weaknesses. Most of the synthesized studies utilized participant self-reporting (i.e., condom use percentage and number of sex partners) to measure effectiveness. The effect of social desirability may have caused research participants to answer questions according to socially expected or accepted norms (Friis & Sellers, 2013), making participant bias a limitation of the evidence. Although nearly impossible to gather, more objective data would have strengthened this evidence, but there was no way to know the true extent of participants' behaviors before study enrollment, and if a participant actually increased their risk-reduction behaviors. Therefore, the evaluation of the treatment's effectiveness may not have been indicative of reality. Additionally, the follow-up period to evaluate the interventions' effectiveness ranged from three to twenty-four months, a period that this investigator believes to be rather short. While the EBIs offer sufficient evidence on the strategies that improve MSM's usage of HIV preventative and risk-reduction behaviors, this evidence does not attest to these interventions' long-term effect. Additionally, none of the referenced studies investigated decision-making, therefore weakening this evidence, as it does not explain MSM's decision-making to implement those behaviors. HIV prevention is an on-going and long-term endeavor of deciding to perform behaviors that reduce one's HIV risks (Caceres et al., 2015; CFA, 2014). Decision-making is the process of weighing different factors surrounding a behavior or choice determining if one will implement the respective behavior (Poortaghi et al., 2015; Popejoy, 2005). The effectiveness of the referenced EBIs' strategies to influence long-term and permanent behavior change is unknown.

### **Health Behavior**

Health behavior is the action patients take to attain information and tools regarding health promotion, risks, and illness (Poortaghi et al., 2015). These actions are ongoing, and may occur purposefully or inadvertently, as individuals perform health behaviors with or without potential or actual health concerns (Poortaghi et al., 2015). A preponderance of evidence exist regarding health behavioral decision-making and is relevant to this study and clinical practice.

### **Health-behavioral Decision-making Research**

Investigators have inquired about health-behavioral decision-making regarding engagement in primary, secondary, and tertiary care. Specifically, studies have been conducted to explore and understand individuals' choices and decisions to initiate or not initiate behaviors related to health promotion (Brown-Kramer & Kiviniemi, 2015; Rao, Lozano, & Taani, 2014; Thom et al., 2016; Wang, Clymer, Davis-Hayes, & Buttenheim, 2015), immunizations (Allan & Harden, 2014; Perez et al., 2015; Wang et al., 2015; Wheldon et al., 2016), screenings and treatment (Bayliss, Duff, Stricker, & Walker, 2017; Brown-Kramer & Kiviniemi, 2015; Mac Bride et al., 2013; Schmidt, Damm, Prenzler, Golpon, & Welte, 2016; Tranberg et al., 2016; Wheldon et al., 2016), and diet and exercise regimens (Bui, Droms, & Craciun, 2014; Kaur, Scarborough, & Rayner, 2017; Kosma, Buchanan, & Hondzinski, 2017), to name a few. There was some variance seen in how investigators conducted decision-making research. The literature showed decision-making research to use sample sizes ranging from five (Schmidt et al., 2016) to 87 (Allan & Harden, 2014). While some studies utilized quantitative methods (Schmidt et al., 2016), most research designs implemented a qualitative methodology, interviewing participants using focus groups or semi-structured interviews (Allan & Harden, 2014; Hussain, Flemming, Murtagh, & Johnson, 2015; Rose, Rosewilliam, & Soundy, 2017).



Decision-making research has been conducted within a variety of contexts. The process of making health choices has been studied from the experiences and perspectives of the patient/patient's legal authority (Allan & Harden, 2014; Coombs, Parker, & de Vries, 2016; Grant, Rodger, & Hoffmann, 2015; Hamilton, Soinks, White, Kavanagh, & Walsh, 2016; Ling, Payne, Connaire, & McCarron, 2015; Lucas, Cabral, Hay, & Horwood, 2015; Perez et al., 2015), the family (Allan & Harden, 2014; Coombs et al., 2016; Grant et al., 2015; Hamilton et al., 2016; Ling et al., 2015; Newson, Povey, Casson, & Grogan, 2013; Nichol, Thompson, & Shaw, 2011; Perez et al., 2015; Siouta et al., 2015), and health professionals (Chong, Aslani, Chen, 2013; Coombs et al., 2016; Rose et al., 2017; Siouta et al., 2015; Thom et al., 2016). Explorations of decision-making did not necessarily compare one group to another; however, the investigators narrowed their inquiry to a specific population. Decision-making has been investigated among different social statuses: low socioeconomic status (SES) (Vesely, 2013), racial/ethnic minorities (Carvajal, Gioia, Mudafort, Brown, & Barnet, 2017; Kosma et al., 2017; Lu, 2017; Mead et al., 2013; Tung, Cook, & Lu, 2012; Vesely, 2013), indigenous persons (Dugas et al., 2017; Gainer et al., 2017; Mitchell, 2011; Tranberg et al., 2016), sexual minorities (i.e., lesbian, gay, bisexual, and transgender persons) (Wheldon et al., 2016), men and women (Kosma et al., 2017; Mead et al., 2013; Tranberg et al., 2016; Wheldon et al., 2016), different age groups (Kosma et al., 2017; Mitchell, 2011; Rao et al., 2014; Wheldon et al., 2016), and specific diagnoses and conditions (Coombs et al., 2016; Gainer et al., 2017; Ling et al., 2015; Mitchell, 2011; Rose et al., 2017; Siouta et al., 2015). Geographically, these studies have been conducted throughout the U.S. (Bui et al., 2014; Thom et al., 2016; Wheldon et al., 2016) and abroad (Grant et al., 2015; Mitchell, 2011; Perez et al., 2015; Siouta et al., 2015). The numerous inquiries in combination with the various contexts health behavioral decision-making research has occurred

provides this investigation the necessary foundation to understand this phenomenon, and reveals the importance and impact health behavioral decision-making research evidence has on clinical practice.

Even in the different contexts that health behavioral decision-making research has occurred, systematic reviews and meta-analyses consistently reveal that decision-making is an individualistic process of weighing and considering various factors (Allan & Harden, 2014; Poortaghi et al., 2015; Schmidt et al., 2016; Tranberg et al., 2016). Factors most commonly involved in health-related decision-making include one's personal and social circumstances like SES and employment, gender, race/ethnicity, culture, religion/spirituality, neighborhood and environment, relationship status, and previous experiences (Poortaghi et al., 2015; Popejoy, 2005). Additionally, knowledge and perspectives (i.e., attitudes, beliefs, myths, and motives) about health, the health behavior, and the disease or condition itself are also weighed in this process (Bui et al., 2014; Clifford, Ryan, Walsh, & McCurtin, 2017; Dugas et al., 2017; Hamilton et al., 2016; Keatley, Clarke, & Hagger, 2013; Newson et al., 2013; Nichol et al., 2011). Replicated studies reporting the same factors in this phenomenon strengthens this evidence's reliability to generalize what is typically involved in health behavioral decision-making.

Although the literature shows the factors of knowledge, personal and social circumstances, and perceptions about health, the health behavior, and the health condition to be involved in health-related decision-making, it is still difficult to generalize and ascertain how each individual values, weighs, views, and processes those factors. The literature inquiries about decision-making occur in homogenous populations, as commonly those with similar backgrounds are more likely to experience and perceive phenomenon in the same way (Popejoy,

2005); however, researchers are cautioned against generalizing. Decision-making is individualistic and value dependent, determined by one's previous and current personal experiences and circumstances (Allan & Harden, 2014; Bui et al., 2014; Clifford et al., 2017; Dugas et al., 2017; Hamilton et al., 2016; Keatley et al., 2013; Newson et al., 2013; Nichol et al., 2011; Popejoy, 2005; Schmidt et al., 2016; Tranberg et al., 2016). Even within narrowed and uniquely defined samples, each person is an outlier, as no one's existence is exactly like another. Therefore, disseminating and applying study implications to the sample's larger population is challenging and limited (Allan & Harden, 2014; Bui et al., 2014; Clifford et al., 2017; Dugas et al., 2017; Hamilton et al., 2016; Keatley et al., 2013; Newson et al., 2013; Nichol et al., 2011; Popejoy, 2005; Schmidt et al., 2016; Tranberg et al., 2016). Despite these limitations, decision-making research provides health professionals with knowledge that allows them to assist patients deciphering between health options (Chong et al., 2013; Coombs et al., 2016; Popejoy, 2005; Rose et al., 2017; Siouta et al., 2015; Thom et al., 2016).

### **Health Professionals' Roles**

Health professionals play an important role in patients' health-related decision-making processes (Chong et al., 2013; Coombs et al., 2016; Popejoy, 2005; Rose et al., 2017; Siouta et al., 2015; Thom et al., 2016), and knowledge gained from health-behavioral decision-making research is used to educate and prepare health professionals to function in that role. Health-related decision-making evidence informs health professionals about what patients know, understand, and perceive about the health behavior and condition (Clifford et al., 2017; Thom et al., 2016). With this knowledge, health professionals are able to clarify patients' misunderstandings, uncertainties, and concerns regarding the particular health option and condition. For example, health professionals can offer coaching and support, assisting patients in

identifying their self-defined goals, applicable choices, and avenues for implementing change (Popejoy, 2005; Thom et al., 2016). Decisional coaching “provide[s] support to patients to achieve quality decisions by . . . assessing patient’s level of decisional conflict, knowledge deficits, [and] their values and [needed] support” (Stacey et al., 2008, p. 25). Similar to the investigator’s conclusion from the EBIs’ evidence, when engaged and engrossed in health related decision-making, patients value open communication and the transparent, non-judgmental exchange of information (Carvajal et al., 2017; Chong et al., 2013; Siouta et al., 2015; Thom et al., 2016). An increased sense of support and advocacy increases behavioral adherence, which improves patient outcomes and successes with health choices (Popejoy, 2005; Thom et al., 2016).

Decision-making research has led to the development and testing of interventions and tools devised to render support and assistance to patients deciding between available health options and treatment (Clifford et al., 2017; Dugas et al., 2017; Llic et al., 2015; Mead et al., 2013). For example, decision aids are complementary tools used to explain and help patients make decisions by providing information about the available options and possible outcomes (Clifford et al., 2017; Dugas et al., 2017; Eggertson, 2010; Stacey et al., 2008). A systematic review of decision aids literature reveals that these tools are treatment-specific and targeted to a specific population affected by a particular disease (Clifford et al., 2017).

### **Health-behavioral Decision-making Literature Synthesis**

Regardless of the context or situation, synthesis of health-related decision-making research defines health decision-making as an individual process of weighing different factors surrounding that behavior or choice that determine one’s implementation or not of that particular behavior or choice (Poortaghi et al., 2015; Popejoy, 2005). The literature shows the common

factors involved in this process to include an individual's social and personal factors, as well as knowledge and perspectives about health, the health behavior, and the disease (Allan & Harden, 2014; Bui et al., 2014; Clifford et al., 2017; Dugas et al., 2017; Hamilton et al., 2016; Keatley et al., 2013; Newson et al., 2013; Nichol et al., 2011; Schmidt et al., 2016; Tranberg et al., 2016). These repetitive factors to be a part of health-related decision-making process demonstrate consistency, strengthening this evidence. Additionally, this evidence is congruent with this study's context, as this study explores how HIV-negative MSM make the decision to initiate PrEP based on their PrEP and HIV knowledge/concerns, social and personal motivations to initiate PrEP, and abilities to adhere to PrEP. Additionally, these concepts are consistent with the conceptualization of decision-making in the Information-Motivation-Behavioral (IMB) skills model. The IMB skills model conceptualizes one's decision to initiate HIV prevention behaviors to be based on their knowledge, motivation, and skills surrounding HIV and HIV risk-reduction behavior (Aliabadi et al., 2015; Amico et al., 2005; Amico et al., 2009; Chang et al., 2014; Fisher & Fisher, 1992; Macapagal et al., 2016; L. Smith et al., 2012). From this synthesis, it was discovered that the proposed study's conceptualization of decision-making is consistent with the literature, demonstrating the significance and contribution this study's findings have on extending the existing decision-making knowledge base.

Decision-making being individualistic and value dependent (Allan & Harden, 2014; Bui et al., 2014; Clifford et al., 2017; Dugas et al., 2017; Hamilton et al., 2016; Keatley et al., 2013; Newson et al., 2013; Nichol et al., 2011; Popejoy, 2005; Schmidt et al., 2016; Tranberg et al., 2016), determines this study's methodology and implications. This review found that most decision-making research is conducted using qualitative methods (Allan & Harden, 2014; Hussain et al., 2015; Rose et al., 2017), and this investigator believes this approach is used to

account for the variances and differences among individuals' experiences and circumstances influencing their decisions. This investigator agrees that factors involved in decision-making are unique and are constructed based on the person's reality and experiences, justifying this qualitative exploration into HIV-negative MSM's PrEP initiation decision-making processes. The uniqueness and individualism of decision-making restricts generalizability, as findings from this inquiry into MSM's PrEP initiation decision-making are reflective of the sampled participants and possibly MSM with similar experiences and circumstances. Therefore, the initial implications this study has in the MSM population and PrEP initiation will not be immediate.

Synthesis of health-related decision-making research implicates the proposed study's impact on clinical practice. As seen with the EBIs, health professionals have a pivotal role in patients' health-behavioral decision-making processes. The literature demonstrates that decision-making research allows health professionals to clarify patients' knowledge and understanding, and can lead to the development and testing of decision tools and interventions (Clifford et al., 2017; Dugas et al., 2017; Llic et al., 2015; Mead et al., 2013). Despite the limitations in transferability, this study's findings educate nurses on ways and topics for counseling and supporting MSM considering PrEP, which can increase HIV prevention through PrEP initiation success. Optimal and accurate PrEP initiation among willing and HIV at-risk persons is the most effective way for PrEP to have the projected impact on the HIV epidemic (CDC, 2016e). This study contributes to establishing a foundation regarding MSM's PrEP initiation decision-making that can be integral in developing more evidence on this phenomenon and evidenced-based and best practice interventions for this population.

### **HIV-negative MSM's Condom-use Decision-making**

As the first pharmacological HIV preventative regimen, PrEP, finding evidence comparable to PrEP initiation decision-making in the context of MSM HIV prevention is difficult. PrEP is indicated in HIV-negative MSM practicing other at-risk behaviors (i.e., intravenous drug use (IDU), unprotected anal/vaginal sex with women, serodiscordant relationship, etc.), but this study investigates PrEP initiation decision-making among MSM who engage in AI with other men. AI is the primary catalyst driving the HIV incidence disparity in MSM, as most MSM report engaging in AI (Meng et al., 2015). Additionally, AI is the riskiest type of sex (CFA, 2014; Pebody, 2010), and the overall most common mode of HIV transmission (CDC, 2016d). While there are other recommendations in reducing MSM's HIV risk during AI, accurate and consistent condom use is the best defense to prevent new HIV infections (CDC, 2015c, 2016c). Not only is condom-use the best behavior to reduce HIV risk, but condom use decision-making is frequently investigated in this population regarding HIV prevention. Therefore, reviewing the literature specific to HIV-negative MSM's condom-use decision-making provides a foundation into MSM's HIV-prevention decision-making processes.

Researchers report that MSM understand that condom use is necessary for HIV prevention (Neville & Adams, 2009; Neville et al., 2016), but MSM recognize that their community's commitment to condom-use consistency is an ongoing challenge. A secondary analysis utilizing data from two previously conducted prospective studies sampling HIV-negative MSM revealed that 84% of MSM do not use condoms consistently (Smith et al., 2015). This outcome demonstrates that MSM's decision-making to use condoms is not due to a knowledge deficit, but to other factors. There is also a consensus that certain situations increase the chances of engaging in unprotected AI (UAI): internet-hook-ups, dating internet sites and applications, and substance abuse (Neville & Adams, 2009; Neville et al., 2016). Researchers

agree that pleasure is another factor in condom-use decision-making, as data showed MSM to deliberately serosort to avoid condoms, as condoms diminish sexual sensations and penile erections (Calabrese et al., 2012; Eaton et al., 2009; Neville & Adams, 2009; Neville et al., 2016). This review was not merely identifying factors influencing MSM's condom-use decision making, but understanding how those factors are processed and rationalized in their decision-making. Therefore, this section of the literature review is organized thematically according to the common concepts apparent in HIV-negative MSM's condom-use decision-making process: HIV concern, psychosocial issues, and relationship dynamics.

### **HIV Concern**

Researchers found that HIV-negative MSM are concerned about contracting HIV (Balan et al., 2013; Neville & Adams, 2009; Neville et al., 2016); however, there is no consensus showing HIV concern to result consistently in MSM deciding to use condoms. Evidence demonstrates that HIV concern is rationalized in the process, but MSM are shown to decrease and increase condom use despite or because of the concern, and various phenomenon: ART success, delayed discounting, barebacking, sexual positions, and “bug-chasers” address the conflicting findings.

Like many Americans, MSM no longer view HIV as a serious problem or public health issue (CDC, 2016b). Data analysis from qualitative studies of 960 participants, mixed-methods studies of 89 participants, and literature reviews of 250 articles have documented the advances in HIV care have diminished HIV concern (Balan et al., 2013; Neville et al., 2016; Neville & Adams, 2009). ART has changed HIV from being a fatal disease, to a chronic disease, which rationalizes some MSM to have UAI, as becoming infected is no longer feared (Balan et al., 2013; Neville & Adams, 2009; Neville et al., 2016).



One example showing a decreased fear and concern in contracting HIV, which influences condom-use decisions, is the concept of delay discounting. As defined by Herrmann et al. (2015), "delay discounting is how sometimes individuals choose less valuable, immediate rewards (e.g., UAI with a risky partner) over more valuable, delayed options (e.g., greater odds of a remaining HIV negative)" (p. 1656). Questionnaires from Herrmann et al.'s (2015) study of 108 MSM practicing UAI revealed that delay discounting is an important factor in condom-use decision-making, as that sample of MSM discounted the value of protected AI, more so than increased HIV protection and concern (Herrmann et al., 2015). In most instances, delayed discounting occurred in the context when a condom was not readily accessible, and immediate gratification had more value than waiting to use a condom (Herrmann et al., 2015). Results showed delay discounting to occur most often in MSM who are younger in age, of a lower SES, abuse substances, routinely engage in sex cognitively impaired, or suffer psychological issues such as depression; however, the investigators reiterated that delayed discounting to be individualistic and value-dependent (Herrmann et al., 2015), which is consistent with decision-making. Delayed discounting is a relatively new concept in the realm of MSM HIV prevention and condom use decision-making, making future research necessary for phenomenal understanding before any conclusions can be determined (Herrmann et al., 2015); however, this evidence indicates that MSM's apparent HIV concern does not always result in consistent condom use.

Barebacking, or the intentional act of engaging in UAI, demonstrates HIV concern exists. Evidence shows that barebacking has been explored as a factor surrounding HIV concern and engaging in unprotected sex (Balan et al., 2013; Bauermeister et al., 2009). Balan et al.'s (2013) investigation of 89 barebacking MSM showed this sample to have HIV concern, however,

instead of using condoms, the concern led to the substitution of condoms with other prevention behaviors: serosorting, occasional condom-use, reducing sexual partners, proof of partner's HIV and STI status, avoiding persons with STIs, touching and masturbation, and cleansing rituals (i.e., washing, enemas, gargling, and urination). Upon reviewing the literature, there is not sufficient evidence to explain the rationale and process behind MSM's decisions to substitute these behaviors for consistent condom use. This lack of knowledge makes it difficult to understand MSM's thought processes, but confirms MSM's concerns for contracting HIV cause them to implement other preventative measures, in addition to occasional condom use.

HIV concern in relation to sexual positioning is also a factor influencing MSM's condom use decision-making. Receptive partners have a significantly higher HIV risk than insertive partners (CDC, 2015c, 2016c; Meng et al., 2015). Neville et al.'s (2016) findings demonstrated that HIV concern associated with sexual positioning is a part of the condom use decision-making process. Concern due to positioning determines a need to use condoms, as explained by one MSM study participant: "we are unwilling to [be on the] bottom without a condom, but we are willing to [be on] top without using one ourselves" (Neville et al., 2016, p. 3594).

Although not as commonly documented, researchers have reported that some MSM have a desire to become infected with HIV (Neville & Adams, 2009). "Bug chasers" is the term for individuals who purposefully engage in UAI with the goal of contracting HIV (Neville & Adams, 2009, p. 133). Due to the higher risk of HIV transmission as the bottom partner, "bug chasers" are primarily the receptive partner and refuse to use condoms (Neville & Adams, 2009). "Bug chasers" are not devoid of HIV concern, as they seek to seroconvert; however, evidence of their rationale for desiring to become positive is unknown. More data are necessary to understand this thought process (Neville & Adams, 2009).

### **Psychosocial Issues**

Social and personal motivations like, psychosocial issues are also involved in MSM's condom use decision-making process. Neville and Adams (2009) identified AIDS fatigue or burnout as a reason justifying UAI. AIDS burnout is "a direct consequence of constant exposure to prevention messages" (Neville & Adams, 2009, p. 133). HIV is a significant national public health issue, as HIV prevention campaigns and messages are scattered about. Qualitative interviews revealed MSM's decision to engage in UAI is a form of social resistance to public standards (Neville & Adams, 2009; Neville et al., 2016). Ironically, decisions to have UAI are supported with the common notion and cliché that it is a man's nature to take risks (Neville et al., 2016). AIDS burnout and social resistance are not common factors a part of decision-making (Neville & Adams, 2009). At present, further research is needed to understand the impact AIDS burnout and social resistance have on MSM's condom use decision-making. Researchers have more commonly reported intrapersonal influences upon condom use decision-making (Bauermeister et al., 2009; Neville & Adams, 2009). Depression, low self-esteem, loneliness, homophobia, and sexual identity conflict are issues and reasons deterring condom use (Bauermeister et al., 2009; Neville & Adams, 2009). This evidence demonstrates that condomless or UAI is an avenue and mechanism to escape these personal hardships (Neville & Adams, 2009), but it is difficult to understand whether MSM with significant intrapersonal prioritize escaping personal-psychosocial hardships over a concern of contracting HIV, which warrants the need for more additional research.

### **Relationship Dynamics**

Relationship dynamics are a factor in HIV-negative MSM's condom use decision-making process (Campbell et al. 2014; Neville & Adams, 2009; Neville et al., 2016). MSM's habit to

use, or not use, condoms depending on the relationship status being open or closed is well documented (Neville & Adams, 2009; Neville et al., 2016). MSM routinely report having protected sex with a casual partner, and having unprotected sex with their main or monogamous partner (Neville et al., 2016). This literature search, however, sought to understand the influence relationship dynamics have on condom use decision-making. Partner conversations and emotions are relationship aspects that MSM commonly state decide condom use.

Partner conversations are a decision-making process of its own, as they involve discussing each persons' sexual risks, preferences, and concerns (Campbell et al., 2014). Campbell et al. (2014) conducted 48 interviews of MSM couples regarding their practice and outcomes from implicit and explicit sexual decision-making discussions. The findings confirm stark differences in the rationales and results from each type of discussion. Explicit discussions among HIV concordant couples involve discussing each partners' HIV and condom-use "concern, boundaries, and level of comfort" (Campbell et al., 2014, p. 704). The discussions allow an open dialogue to express each person's perspective regarding the risks and benefits of UAI given their relationship status (Campbell et al., 2014). Campbell et al. (2014) found that a similar process occurs between HIV discordant couples, but the discussions pertain to each partner's comfort level with the HIV risk for the uninfected partner given the positive person's HIV treatment, viral load, and CD4 count. With viral suppression, TasP rationalize their decision to have UAI, as HIV transmission risk is significantly decreased (Campbell et al., 2014). On the other hand, implicit conversations do not allow partners to acknowledge each other's risks and concerns (Campbell et al., 2014). The decision to not use condoms is "just understood", as the absence of the "full picture of their partner's testing and sexual history"

rationalizes UAI (Campbell et al., 2014, p. 704). Despite MSM's knowledge of AI being an HIV risk factor, without a definitive cause of concern, condom-less sex is acceptable.

Other researchers have investigated and found that emotions to rationalize decisions about condom use (Bauermeister et al., 2009; Goldenberg et al., 2015; Green et al., 2014). Studies by Goldenberg et al. (2015) and Greene et al. (2014) found that love, intimacy, and trust between partners decrease condom use. Green et al. (2014) had 23 MSM couples complete questionnaires and interviews while Goldenberg et al. (2015) conducted interviews and analyzed diary entries from 25 MSM about the influences of relationship characteristics on condom use decision making. The presence of love, intimacy, and trust lower the perception of their partner's HIV risk and concern, justifying UAI (Bauermeister et al., 2009; Goldenberg et al., 2015; Green et al., 2014). Lust is another emotion integral to condom use decision-making. Although lust does not alter risk perception (Goldenberg et al., 2015), lust rationalizes UAI, as the desire and immediate gratification from UAI is worth the risk (Herrmann et al., 2015).

### **HIV-negative MSM's Condom-use Decision-making Literature Synthesis**

Synthesis of this literature is consistent with previous explorations of health-related decision-making research. From this evaluation of MSM's condom-use decision-making research, health-related decision-making is revealed to be a process of evaluating and assessing the different personal, social, and knowledge factors surrounding that choice (Poortaghi et al., 2015; Popejoy, 2005). This evidence confirms that even in a homogenous group, decision-making is unique, individualistic, and value dependent (Allan & Harden, 2014; Bui et al., 2014; Clifford et al., 2017; Dugas et al., 2017; Hamilton et al., 2016; Keatley et al., 2013; Newson et al., 2013; Nichol et al., 2011; Popejoy, 2005; Schmidt et al., 2016; Tranberg et al., 2016). This

conclusion provides further validation of this study's conceptualization of decision-making, but also has significant implications for the proposed study's findings.

Research showed MSM know that condom use is necessary for HIV prevention (Neville & Adams, 2009; Neville et al., 2016), but MSM still have inaccuracies and misconceptions about HIV prevention strategies. Balan et al. (2013) reported MSM still believe cleansing rituals like washing, enemas, gargling, and urination are appropriate substitutes to condom use. Cleansing rituals have never been an approved HIV prevention behavior since the first HIV incidence in the 1980s. In addition, MSM still errantly rely on perceptions and emotions to determine a current or potential partner's HIV risk/status and their decision to use condoms (Bauermeister et al., 2009; Campbell et al., 2014; Goldenberg et al., 2015; Green et al., 2014). Therefore, this evidence indicates to the investigator that misconceptions and elements of trust are aspects of MSM's condom-use decision-making process, warranting the need for decision-making research, especially with PrEP, a new and unique prevention modality.

As the newest and first pharmacological HIV preventative agent, this investigator concludes that there may be some possible inaccurate information regarding HIV prevention through PrEP initiation. Exploring HIV-negative MSM's decision-making processes to initiate PrEP may uncover such misconceptions regarding HIV or PrEP. Due to PrEP's distinct differences from condoms (i.e., ADR, nephrotoxicity, bone density loss, and unknown adverse events) (CDC, 2014b), knowledge of the decision-making process is imperative to ensure MSM accurately understand PrEP's clinical indications, instructions, and consequences. From these findings, nurses can devise education and counseling tools that target HIV and PrEP knowledge inaccuracies and deficits.

Health behaviors can occur with or without an actual concern (Poortaghi et al., 2015); however, this literature evidence on HIV-negative MSM's condom-use decision-making consistently documented HIV concern as a factor in this process. Despite MSM having any HIV concern, there is no consensus on how that concern determines MSM's decision to use or not use condoms. Despite the lack of consensus regarding how HIV concern influences condom use, the consistency of HIV concern to appear in condom-use HIV prevention decision-making is the strength of this evidence, and leads to the conclusion that HIV prevention decision-making is best understood in the context of HIV concern. For that reason, exploring MSM's PrEP initiation decision-making based on HIV concern is a part of this study's objective. However, this concept is inconsistently defined, as none of the articles explicitly defined concern. Participants, investigators, and readers can have their own conceptualization of concern. In Neville and Adams' (2009) and Neville's et al. (2016) studies, concern is assumed to pertain to susceptibility to contracting the virus. While Balan et al.'s (2013) qualitative analysis perceive concern to be the difficulties and challenges associated with being HIV positive. The investigator believes that having both definitions represented in the literature to have equal merit and relevance to condom-use decision-making, therefore, both types of concern are incorporated into the proposed study's investigation into MSM's PrEP initiation decision-making processes. The ambiguity associated with how each study defines concern is related to the inconsistency of researchers to identify or utilize theoretical frameworks that define the conceptualization of HIV concern. Therefore, another significant finding from this review is the importance of applying an appropriate theoretical framework.

### **IMB Skills Model in MSM's HIV Prevention Research**

The IMB skills model guides this study, as it conceptualizes the decision to initiate HIV risk-reduction behaviors as involving one's information, motivation, and skills (Aliabadi et al., 2015; Amico et al., 2005; Amico et al., 2009; Chang et al., 2014; Fisher & Fisher, 1992; Macapagal et al., 2016; L. Smith et al., 2012). Fisher and Fisher (1992) developed this conceptualization of HIV-related behavior change by conducting an extensive review of AIDS risk-reduction literature. Information is the knowledge, myths, and means known to reduce HIV risk; motivation is the attitudes, beliefs, and perceived social support regarding the preventative behavior; and behavioral skills are the abilities to perform that behavior (Aliabadi et al., 2015; Amico et al., 2005; Amico et al., 2009; Chang et al., 2014; Fisher & Fisher, 1992; Macapagal et al., 2016). This model assumes an individual's culture, values and beliefs, social standing, SES, environment, and life circumstances determines their understanding, motivation, and abilities regarding their decision-making to utilize HIV preventative behaviors (Aliabadi et al., 2015; L. Smith et al., 2012; Traube et al., 2011), but those factors are not represented in the model. The absence of these personal demographic characteristics in the model is a limitation, as it does not provide the complete process involved in initiation of HIV prevention decision-making (Traube et al., 2011). Despite this limitation, the IMB skills model represents factors shown to influence initiation of HIV risk reduction behaviors, and is consistent with health-related and HIV-negative MSM's condom-use decision-making processes.

The literature shows investigators to use this model to study condom usage in HIV-negative MSM (Macapagal et al., 2016), PLWH medication adherence and retention in care (Amico et al., 2005; Amico et al., 2009; Horvath et al., 2014; Rongkavilit et al., 2010; L. Smith et al., 2012), and to develop and test interventions (Aliabadi et al., 2015; Chang et al., 2014). To account for variances in HIV prevention behavioral decision-making, Aliabadi et al. (2015)



states that using a qualitative approach is appropriate with the IMB skills model so information can be elicited using dialogue and open-ended questions. Adherence to this recommendation is apparent, as the IMB skills model is commonly applied in large qualitative studies using semi-structured interviews and focus groups (Chang et al., 2014; Horvath et al., 2014; Macapagal et al., 2016; Rongkavilit et al., 2010) with samples utilizing 96 (Macapagal et al., 2016) to 312 participants (Horvath et al., 2014). Therefore, the evidence validates the investigator's chosen methodology for conducting this exploration into HIV-negative MSM'S PrEP initiation decision-making processes.

### **MSM and PrEP**

Despite FDA approval in 2012, there is a paucity of literature on PrEP initiation decision-making in any population. Most of the available literature pertains to PrEP's pre-approval clinical trials, effectiveness and efficacy, health professionals' perspectives, and clinic start-ups. Therefore, this literature review establishes the knowledge base for the proposed study by synthesizing the available evidence of MSM's PrEP interest, initiation, and decision-making.

### **Interest**

Although only 25% of MSM in America report being knowledgeable of PrEP (Al-Tayyib, Thrun, Haukoos, & Walls, 2014; Raifman, Flynn, & German, 2017), PrEP interest is high in the MSM community. Studies show MSM's PrEP interest arises from a desire to promote health and enhance sexual pleasure (Brooks et al., 2012; Collins et al., 2016; Gamarel & Golub, 2015; Garcia & Harris, 2017; Golub, Gamarel, Rendina, Surace, & Lelutiu-Weinberger, 2013; Mimiaga, Closson, Kothary, & Mitty, 2014; Oldenburg et al., 2016; Taylor et al., 2014). These studies sampled anywhere from 19 to 699 MSM in serodiscordant relationships through semi-structured interviews, focus groups, and online and paper questionnaires in Boston, MA;

Pittsburg, PA; San Juan, Puerto Rico; and Atlanta, GA. PrEP is believed to empower MSM to practice proactive HIV prevention as opposed to post-exposure reactivity (Oldenburg et al., 2016). During PrEP clinical trials, MSM study participants were motivated to participate to “protect themselves” and to assist in preventing future infections (Taylor et al., 2014, p. 875). Due to condom failures and inconsistent use, MSM found comfort in PrEP’s added protection (Collins et al., 2016). The added protection reduces anxiety and shame associated with risky sexual behaviors, as well as reduces fears of contracting the virus when MSM have AI with a person with a positive or unknown HIV status (Brooks et al., 2012; Collins et al., 2016; Mimiaga et al., 2014; Oldenburg et al., 2016; Taylor et al., 2014).

Researchers found that MSM believe an increase in UAI will be a motivating factor leading to their peers’ decision to initiate PrEP (Brooks et al., 2012; Collins et al., 2016; Garcia & Harris, 2017; Golub et al., 2013; Oldenburg et al., 2016; Perez-Figuerora et al., 2015; D. Smith, Toledo, Smith, Adams, & Rothenberg, 2012; Taylor et al., 2014). Risk compensation is the purposeful increase in HIV risky behaviors while taking PrEP (Blackstock et al., 2016; Calabrese et al., 2014; Calabrese & Underhill, 2015; Karris et al., 2014; Yagoda & Moore, 2016). Findings from PrEP clinical trials did not show any evidence of risk compensation to occur (CDC, 2014b; Marcus et al., 2013; McCormack et al., 2016; Mugwanya et al., 2013), but it is speculated that PrEP may lead to intentional UAI for increased intimacy and pleasure (Collins et al., 2016; Gamarel & Golub, 2015), which is lost when using condoms (Calabrese et al., 2012; Calabrese & Underhill, 2015; Higgins & Wang, 2015). These perspectives, however, are only assumptions, as the problem is that MSM’s PrEP initiation decision-making processes are unknown.

## **Initiation**

Gilead® surveyed U.S. retail pharmacies about the occurrence of patients filling a PrEP prescription for the first time during 2012 and 2015 (NAM, 2018). During the three year period, 49,158 patients were dispensed their initial PrEP prescription from a reporting pharmacy (NAM, 2018). Most patients initiating PrEP are White (74%) followed by Hispanics (12%), African-Americans (10%), and Asians (4%) (NAM, 2018). This data also show males (79%) to initiate PrEP more commonly than women (NAM, 2018). Lastly, the data indicates that PrEP patients are older in age, as 8% of patients are younger than 25 years of age (NAM, 2018). This recent data from Gilead® is similar to initial statistics about PrEP patients, as Rooney (2013) reported the average PrEP patient is 37 years of age and male. Furthermore, researchers consistently report most current and former PrEP patients are MSM (Krakower et al., 2015; Rooney, 2013; Tellalian et al., 2013). Despite MSM being the most common PrEP consumers, approximately 3% of the MSM population are or have ever initiated PrEP (Krakower & Mayer, 2015). The literature offers speculated reasons as to why PrEP initiation is low, not only in MSM, but nationally as well.

Poor PrEP initiation is speculated to be the result of structural barriers (Auerbach et al., 2015; Flash et al., 2014; Oldenburg et al., 2016; Perez-Figueroa et al., 2015; Rolle et al., 2017; Taylor et al., 2014; Underhill et al., 2014; D. Smith et al., 2012). Stigma is a barrier to PrEP initiation from survey (Dolezal et al., 2015; Eaton et al., 2014; Oldenburg et al., 2016), focus group (D. Smith, et al., 2012; Taylor et al., 2014), and semi-structured interview studies (Collins et al., 2016; Golub et al., 2013; Perez-Figuerora et al., 2015). These studies have occurred throughout the U.S., but primarily in areas with high HIV rates and MSM populations: Atlanta, GA; Baltimore, MD; Boston, MA; New York, NY; Pittsburg, PA; San Juan, Puerto Rico, and Seattle, WA utilizing samples of 14 to 699 MSM. PrEP patients are stigmatized as “Truvada

whores”, undermining HIV prevention and PrEP initiation (Calabrese & Underhill, 2015; Haire, 2015). Perceived negative stigma and judgmental reactions from peers and health professionals are believed to deter MSM from seeking and initiating PrEP (Auerbach et al., 2015; Collins et al., 2016; Dolezal et al., 2015; D. Smith, et al., 2012); however, this is only a presumption.

Another barrier to PrEP initiation is inaccessibility due to high cost and lack of insurance coverage (Oldenburg et al., 2016; Perez-Figueroa et al., 2015; Rolle et al., 2017; D. Smith et al., 2012; Taylor et al., 2014). Patients are more willing to use PrEP if it is conveniently available at minimal or no cost (Golub et al., 2013; D. Smith et al., 2012). Insurance coverage and cost does not only implicate the ability to purchase the drug, but returning for required routine follow-up care at least quarterly (Oldenburg et al., 2016; Perez-Figueroa et al., 2015; Rolle et al., 2017; D. Smith et al., 2012; Taylor et al., 2014). Rolle et al. (2017) conducted a study among 184 PrEP eligible young Black MSM to understand PrEP initiation in this population in the absence of accessibility and cost barriers. In this MSM sample, 63% ( $n=116$ ) expressed PrEP interest and were notified that participation provided them with access to the medication and required follow-up care at no cost (Rolle et al., 2017). Despite these favorable conditions, only 34% ( $n=63$ ) actually initiated PrEP (Rolle et al., 2017); however, the study provides no evidence explaining how participants made their decision. Even in the absence of structural barriers, initiation was less than optimal, therefore, leading this investigator to presume that the decision to initiate PrEP to encompass more than overcoming structural barriers, and reiterates the need for the proposed study's inquiry into MSM's PrEP initiation decision-making processes.

### **Decision-making**

This literature review contained two publications regarding PrEP decision-making in MSM. Garcia and Harris (2017) analyzed survey results from their study of 159 Latino MSM

currently taking PrEP in San Antonio, TX. Garcia and Harris (2017) found that the main reason for initiating PrEP was that the participants had multiple sex partners (34.7%) and did not want to become HIV infected (40%). Only 1.6% of the sample evaluated engagement in condom-less sex as a reason to initiate PrEP (Garcia & Harris, 2017). One other article explored MSM PrEP patients' experiences taking PrEP in a real-world context. Parker et al. (2015) conducted qualitative interviews of 24 MSM PrEP patients in Providence, RI. Most participants engaged in inconsistent or condom-less sex and did not use any other HIV preventative behaviors (Parker et al., 2015). The participants were currently on PrEP and had been on the regimen for at least three months prior to study participation. Patient interviews surrounding PrEP experiences included a variety of topics: cost and insurance issues, risk compensation, interest, and which medical specialties were providing PrEP. Parker et al. implied that MSM's decisions to initiate PrEP were made in order to reduce their risk or concern of contracting HIV. Additionally, participants reported that despite being on PrEP, choosing to use condoms is still a complex process; however, the participants did not show evidence of risk compensation, as there was not a reported increase in HIV risky encounters and behaviors (Parker et al., 2015).

Other available evidence on PrEP initiation decision-making is speculative. From this review, two articles provided knowledge of MSM's condom-use decision-making in the hypothetical context of PrEP. Koblin et al. (2011) inquired about the efficacy of PrEP's influence on condom use decision-making among a sample of 630 MSM who engaged in both UAI and in AI while under the influence of alcohol or non-injection drugs. At the time the study was conducted, PrEP's efficacy was definitively unknown; therefore, Koblin et al. (2011) utilized PrEP's efficacy uncertainty as a variable to gauge condom-use decision-making. Most of Koblin and colleagues' high-risk sample reported that they would eliminate condom-use only

if PrEP has a moderate to maximal efficacy, as it reduces the level of HIV concern for contracting the virus (Koblin et al., 2011). Although this evidence reiterates the importance HIV concern plays in HIV-prevention decision-making, this evidence would have more significance if conducted in a sample with less HIV risk factors. This HIV high-risk sample already engaged in UAI in the absence of PrEP, and this investigator believes the research purpose would have had more meaning in a sample of MSM reporting consistent condom use. Therefore, these results only validate the need for PrEP availability.

On the other hand, Hoff et al. (2015) qualitatively explored anticipated condom use among 48 MSM in HIV-negative concordant ( $n=26$ ) and discordant couples ( $n=22$ ) (Hoff et al., 2015). Findings were not conclusive, as results equally reported participants to continue and discontinue condoms in conjunction with PrEP (Hoff et al., 2015). Additionally, most participants viewed the decision to initiate PrEP to be made after engaging in an explicit conversation with their partner (Hoff et al., 2015). Although seemingly favorable, these results do not provide any significance, as the investigators did not collect couples' current condom-use habits. Therefore, the effect PrEP would have on condom-use in this sample cannot be determined. In regards to decision-making, this evidence does not provide any data on MSM's PrEP initiation decision-making processes, as the study's occurred in the hypothetical context of PrEP.

### **MSM and PrEP Literature Synthesis**

This evidence concluded that MSM's PrEP initiation decision-making process is currently insufficient for understanding this phenomenon. Demographic and statistical data on PrEP initiation demonstrates that the most HIV-vulnerable population, MSM, is initiating PrEP. Although that data is optimal, these survey findings cannot determine these patients HIV risks

and PrEP clinical indications, or their decision-making processes to initiate PrEP. Evidence from Hoff et al. (2015) and Koblin et al. (2011) is speculative, and Garcia and Harris's (2017) research findings only reveal that MSM initiate PrEP out of the behaviors and factors they perceive to increase their HIV risk and concern. While this is a part of decision-making, this evidence does not provide the depth necessary to contribute to decision-making literature, as the factors and processes involved in how MSM derive to their decision is absent.

### **Knowledge Gap**

Research into MSM's PrEP initiation decision-making is imperative. The literary findings cause one to presume that MSM to currently have HIV prevention misconceptions and may have misconceptions about PrEP. PrEP is a complementary regimen, and is to be used in combination with other HIV prevention behaviors, especially consistent condom use (CDC, 2014b). This review's synthesis of the few studies specific to MSM and PrEP showed MSM have a misconception about this requirement, and demonstrates that MSM will require support, education, and behavioral counseling when considering PrEP initiation. Due to the implications of decision-making evidence, research into PrEP decision-making from actual patients is necessary (Hoff et al., 2015; Koblin et al., 2011) to understand what MSM patients know and understand about PrEP.

The proposed study is foundational evidence to fill this knowledge gap. Decision-making details what and how individuals consider and evaluate the different factors surrounding a choice or option (Poortaghi et al., 2015; Popejoy, 2005). The study's objective is to explore how HIV-negative MSM decide to initiate PrEP based on their: (a) PrEP knowledge and HIV concern(s)/risk(s); (b) personal and social motivations to initiate PrEP; and (c) behavioral skills

and abilities to adhere to PrEP. Knowledge from this study details the factors and aspects that are considered and weighed during the PrEP initiation decision-making process.

### **Summary**

In summary, the personal endeavor of decision-making makes a qualitative approach appropriate, as this methodology gives voice to the emic view and participants' realities and perspectives (Streubert, 2014; Toles & Barroso, 2014b). Health professionals, however, should be cautious in determining study implications, as even in the presence of consistent and replicated evidence, personal and social perspectives and circumstances make generalizing study findings difficult (Bauermeister et al., 2009; Campbell et al. 2014; Goldenberg et al., 2015; Greene et al., 2014; Herrmann et al., 2015; Neville & Adam, 2009). Despite the transferability limitations, decision-making research is still valuable, as decision-making research allows health professionals to clarify patients' knowledge and understanding (Clifford et al., 2017; Dugas et al., 2017; Llic et al., 2015; Mead et al., 2013). Information gleaned from the proposed study educates nurses about the topics and techniques needed to support and coach patients during this process. This study lays the foundation for nursing research, as future studies are replicated to develop and refine these findings. Additionally, this foundational study can contribute to the development and testing of decision tools and interventions, which can be used to assist and educate patients during PrEP initiation decision-making process. That evidence can determine the best strategies for achieving MSM HIV PrEP prevention success.

The literature shows health-related decision-making to be an individual process of weighing different personal, social, and knowledge factors surrounding that behavior or choice (Poortaghi et al., 2015; Popejoy, 2005). While the literature exhibits a consensus that these are the primary factors involved in health-related decision-making, there is no consensus on how



each individual evaluates and views these factors. These factors are value dependent, influenced by previous and current circumstances (Allan & Harden, 2014; Bui et al., 2014; Clifford et al., 2017; Dugas et al., 2017; Hamilton et al., 2016; Keatley et al., 2013; Newson et al., 2013; Nichol et al., 2011; Popejoy, 2005; Schmidt et al., 2016; Tranberg et al., 2016). Research also demonstrates individuals perform health behaviors consciously or subconsciously aware of health concerns (Poortaghi et al., 2015), but MSM's condom-use decision-making found HIV concern to be consistently a part of the process (Balan et al., 2013; Bauermeister et al., 2009; Campbell et al. 2014; Neville et al., 2016; Neville & Adams, 2009). This investigator concludes concern to be an influential factor into HIV prevention behavior decision-making, which now extends to PrEP initiation. PrEP initiation is deliberate, as it is initiated purposefully and intentionally out of a personal HIV concern. Two types of concern are apparent in the literature (i.e., HIV concern regarding susceptibility and concern about living with the virus), and both concern types have merit in deciding HIV preventative behaviors and this exploration.

The CDC's compendium demonstrates that knowledgeable health professionals are integral to increasing MSM's use of risk-reduction behaviors, as MSM need support and guidance from a professional, trusted resource, or program knowledgeable in HIV prevention in order to increase utilization of HIV risk reduction behaviors (CDC, 2017a, 2017c). Additionally, the compendium revealed that MSM are receptive to the counseling and support rendered by health professionals with a respectful and non-judgmental rapport. Health professionals' abilities to intervene during the decision-making process are imperative for MSM, as this review shows misconceptions regarding HIV prevention behaviors still exist. PrEP initiation presents potential risks unlike any other HIV preventative intervention (i.e., acquired drug resistance (ADR), nephrotoxicity, bone density loss, and unknown adverse events) (CDC, 2014b), making

knowledge of the understandings, motives, and abilities MSM patients have determining their decisions to initiate PrEP imperative to their overall health.

While studies by Garcia and Harris (2017) and Parker et al. (2017) offer some evidence into this population's decision-making, these investigations' research designs and questions only validate and confirm MSM initiate PrEP to prevent HIV, which is a known and appropriate clinical indication. Structural barriers are believed to be factors in MSM's decision-making process, but this belief has not been evaluated. Research in PrEP decision-making from actual patients is necessary to understand the phenomenon of PrEP initiation (Hoff et al., 2015; Koblin et al., 2011). The proposed investigation contributes to filling this knowledge gap, as the purpose is to explore MSM's decision to initiate PrEP based upon their evaluation and perceptions pertaining: (a) PrEP knowledge and HIV concern(s)/risk(s); (b) personal and social motivations to initiate PrEP; and (c) behavioral skills and abilities to PrEP adherence.

### Chapter 3: Methodology

The methodology for this study was Sandelowski's qualitative description. Qualitative description is rooted in naturalistic research and constructivism, used to gather, understand, and describe individuals' authentic experiences (Colorafi & Evans, 2016; Neergaard et al., 2009; Polit & Beck, 2012; Sandelowski, 2000, 2010; Willis, Sullivan-Bolyai, Knafl, & Cohen, 2016). Naturalistic research is best when studying a new phenomenon, so that participants can speak their truth, uninfluenced by outsiders' expectations, as each individual's personal, social, and environmental factors shape human experiences, and this methodology focuses on understanding the contextual, cultural, personal, and social aspects of a phenomenon (Creswell, 2013; Frey et al., 1999; Polit & Beck, 2012; Willis et al., 2016).

Health-behavioral decision-making is the process of weighing different factors surrounding a behavior or choice, which determines if one will implement or not implement the respective behavior or choice (Poortaghi et al., 2015; Popejoy, 2005). Decision-making is individualistic and value dependent, determined by one's previous and current experiences and circumstances (Allan & Harden, 2014; Bui et al., 2014; Clifford et al., 2017; Dugas et al., 2017; Hamilton et al., 2016; Keatley et al., 2013; Newson et al., 2013; Nichol et al., 2011; Poortaghi et al., 2015; Popejoy, 2005; Schmidt et al., 2016; Tranberg et al., 2016). Other factors commonly involved in health-behavioral decision-making include one's knowledge and perspectives about health, the behavior, and the disease (Bui et al., 2014; Clifford et al., 2017; Dugas et al., 2017; Hamilton et al., 2016; Keatley et al., 2013; Newson et al., 2013; Nichol et al., 2011). The personal nature of decision-making is congruent with qualitative description's philosophical view to understand and describe authentic experiences (Colorafi & Evans, 2016; Neergaard et al., 2009; Sandelowski, 2000, 2010; Willis et al., 2016).

The Information-Motivation-Behavioral (IMB) skills model guided this inquiry, as it conceptualizes HIV risk-reduction decision-making to include an individual's knowledge, motivation, and skills regarding the HIV prevention behavior (Aliabadi et al., 2015; Amico et al., 2005; Chang et al., 2014; Fisher & Fisher, 1992; Macapagal et al., 2016; L. Smith et al., 2012). In this framework, knowledge includes all the information, both accurate and mythical, about the preventative behavior; motivation encompasses social and personal support and perspectives regarding the behavior; and behavioral skills are the necessary abilities to perform the behavior (Aliabadi et al., 2015; Amico et al., 2005; Amico et al., 2009; Chang et al., 2014; Fisher & Fisher, 1992; Macapagal et al., 2016); however, MSM's HIV prevention literature showed that HIV concern is also a factor in their decision-making. Therefore, consistent with the model's concepts and the literature, this study explored HIV-negative MSM's PrEP initiation decision-making based on their (a) PrEP knowledge and HIV risk(s)/concern(s); (b) personal and social motivations to initiate PrEP; and (c) behavioral skills and abilities to PrEP adherence. Similar to decision-making literature, a qualitative approach is best when using this model, as the use of dialogue and open-ended questions will allow the phenomenon to be explored in-depth (Aliabadi et al., 2015).

Conducting one-on-one semi-structured interviews was the method for collecting data, as it offered several benefits to the study's findings and participants. One-on-one interviews provided each participant increased anonymity given the stigma surrounding their sexual identity and PrEP (Calabrese & Underhill, 2015; Haire, 2015). This method allows an exploration into participants' PrEP initiation decision-making processes authentically and uninfluenced by others, giving a voice to the emic view (Hutchinson, Wilson, & Wilson, 1994; Streubert, 2014). Lastly, this qualitative research may have provided a therapeutic benefit to participants, as expressing

their feelings and perspectives in an open conversation could have fostered an internal feeling and sense of acknowledgement, catharsis, purpose, and empowerment (Hutchinson et al., 1994).

Conducting this study with a qualitative description design implicates clinical practice and future studies. Qualitative description is appropriate when there is a need to answer questions influencing clinical practice (Sandelowski, 2000). Additionally, qualitative studies are also indicated and useful in research instrument development (i.e., decision aids and coaching strategies) (Toles, & Barroso, 2014b). Health professionals are advocates in patients' decision-making processes, rendering support and education to patients when choosing the treatment course and option best suited and congruent with patients' self-identified health goals (Carvajal et al., 2017; Chong et al., 2013; Mead et al., 2013; Popejoy, 2005; Rose et al., 2017; Stacey et al., 2008; Tariman & Szubski, 2015; Thom et al., 2016). This study's findings of MSM's knowledge, motivations, and skills to initiate PrEP revealed this sample's PrEP knowledge, and their perceptions regarding their HIV risk(s)/concern(s) also revealed their understanding about HIV. With this data, health professionals are able to identify opportunities to assist patients in resolving occurrences of internal and external conflict, PrEP and HIV etiology misunderstandings, or other concerns when deciding to initiate PrEP. Findings from this study help identify factors influencing MSM's PrEP initiation decision-making process and may provide content for health professionals to educate, support, and coach patients during this process. The proposed study is foundational, extending the knowledge base of health-behavioral decision-making, HIV prevention, and MSM and PrEP initiation, contributing to future development of evidenced-based strategies and tools best for counseling and supporting MSM during this process leading to HIV prevention success through PrEP initiation. This chapter details the study procedures the investigator followed to conduct this study.

### **Study Procedures**

Study procedures explicitly describe the process for recruiting and collecting data from participants. For a qualitative investigation to be trustworthy, the study procedures must match and align with the research objective, literature findings, theoretical framework, and methodology (Colorafi & Evans, 2016; Neergaard et al., 2009). Although the timeframe for performing and conducting a study from start to completion cannot be predetermined, the investigator anticipated this study to be conducted over a twelve-month period. Appendix C displays the timeline of study milestones from study approval to study closure.

### **Human Subjects' Protection**

Protecting the safety and confidentiality of research participants included receiving the appropriate approvals and securing participant data. The investigator received approval from Kennesaw State University's (KSU) Institutional Review Board (IRB) in March 2018, and adhered to their research and ethical principles. Additionally, the investigator sought and received approvals from identified and consenting PrEP practices' administrations and research departments between March and August of 2018. Interested patients meeting the inclusion criteria underwent informed consent, and after giving written informed consent, the participant was enrolled into the study, assigned a participant identification (PID) number, and provided a pseudonym. When disseminating this study's findings in publications or conference presentations, the investigator will refer to the participants using their pseudonym or PID number.

Upon the completion of the written consent and enrollment forms, the documents were scanned and saved onto a password protected and encrypted thumb drive. All hardcopy forms were locked and maintained in the investigator's office. Each participants' audio recordings,

transcripts, data analyses, and field notes were identified according to the participant's PID number and scanned and saved on the thumb drive. Study related materials (i.e., thumb drive, audio recordings, transcripts, etc.) were kept in a locked cabinet in the investigator's office. This information will be stored in the investigator's locked office three years post-study closure or according to KSU's IRB's guidelines. Once the span of time has expired, all study related materials will be shredded and discarded according to KSU's guidelines.

### **Setting**

The setting is the place where participant recruitment will occur. Participants were recruited from identified clinics with from providers offering PrEP and PrEP services; however, interviews occurred at the recruitment clinic, public library, office, conference room or location providing participants with comfort, privacy, and anonymity.

*Identify PrEP clinics.* Recruitment for qualitative studies typically occur in an area commonly affiliated with, or frequented by the study population of interest (Toles & Barroso, 2014a). The proposed study sought to identify HIV-negative MSM's PrEP initiation decision-making process; therefore, participant recruitment targeted MSM PrEP patients. Since PrEP is a preventative regimen, there is no funding source for these clinics, as federal and state programs like the AIDS Drug Assistance Program (ADAP), and Ryan White Care Act Part B only fund HIV/AIDS' treatment efforts, not prevention efforts (Horberg & Raymond, 2013; McMahan et al., 2014). As a preventative regimen, any clinician with prescribing authorities or capabilities can prescribe PrEP, but from this investigator's own experience, most PrEP clinics are started as another service or discipline within an HIV clinic. Additionally, patients are referred by word of mouth from peers or from accessing a service in a facility that provides PrEP. Therefore, the investigator identified clinics with health professionals known and documented to offer PrEP

services in the states of Alabama and Georgia. The investigator searched the Greater Than AIDS website, <https://greaterthan.org/get-prep/PrEP>, a site used to provide HIV/AIDS information including clinics and providers known to offer PrEP. The investigator also identified PrEP clinics and providers by gathering information from Alabama's and Georgia's state health departments' HIV/AIDS division, and Appendices D and E provide a list of those identified clinics and providers. Due to slow recruitment, the investigator identified other PrEP clinics and providers in other parts of the Southern U.S. using the Greater Than AIDS website and respective state health departments' HIV/AIDS divisions. Specifically, the investigator contacted clinics in Florida, Mississippi, and Louisiana to gauge their interest in participating.

*Access PrEP clinics.* Once identified, the investigator contacted the PrEP clinics for permission to recruit study participants. Each contacted practice received a recruitment invitation letter and study synopsis (see Appendices F and G, respectively). The investigator requested a face-to-face meeting with the necessary administration and staff to further describe the study and to answer any questions; however, most correspondences occurred through electronic mail (email) and phone conversations. Once granted permission to recruit, the investigator provided recruitment handouts and posters (see Appendix H and I, respectively) to those consenting facilities. Clinic staff disseminated or made the recruitment materials available and visible to patients in waiting areas and examination rooms. By this recruitment strategy, patients made the choice to participate in the study, which was thought to make providers feel more comfortable with supporting the study, as the investigator did not have access to patient records. The handout had a brief study synopsis and the investigator's contact information. With the permission of the facility, the investigator was willing to be on-site during clinic hours



at least once a week to recruit and answer questions from staff and patients. Given the fact that these clinics provided services and care to PLWH, such permissions were not granted.

### **Sample**

Although qualitative descriptive researchers commonly use purposeful sampling, as it gives researchers immediate access to the population specifically experiencing the investigated phenomenon (Colorafi & Evans, 2016; Neergaard et al., 2009; Sandelowski, 2000), but the investigator used convenience and snowball sampling. Convenience sampling is “the use of the most readily accessible persons” as research participants (Haber, 2014, p. 236), as participant recruitment occurred at PrEP clinics that were not specific to serving MSM alone. As the investigator identified study participants, snowball sampling occurred as she asked participants to refer the study to other potential study participants (Polite & Beck, 2012).

In qualitative studies, an exact sample size is difficult to predict, as data saturation determines the sample size. Although an exact number of participants can be difficult to estimate, researchers have given guidance on potential sample size for qualitative research studies. Recommendations for understanding the essence of experiences tend to have a sample of six (Sandelowski, 1995). Mason (2010) stated that the average sample size used in doctoral qualitative research studies was 31. For a fairly homogenous group, data saturation could occur with a sample size of 12 (Boddy, 2016). Similarly, Toles and Barroso (2014a) concluded that a sample size of less than 30 participants is best given the significant amount of text to be analyzed. A systematic review reported qualitative descriptive sample sizes to use between 11 and 20 participants (Kim, Sefcik, & Bradway, 2017). Lastly, Parker et al.'s (2015) qualitative inquiry of MSM PrEP patient experiences used 24 participants. Therefore, given the variances in

qualitative studies' sample size, the investigator anticipated a sample size of 10 to 30 participants in order to achieve data saturation.

***Inclusion criteria.*** To be eligible for this study, participants had to meet all of the following inclusion criteria at the time of consent: (a) assigned a sex of male at birth; (b) 18 years of age or older; (c) verbally confirm engagement in anal intercourse (AI) with men; (d) currently taking PrEP; (e) began taking PrEP in the past six months; (f) verbally confirm being HIV-negative; (g) read, speak, understand, and write English; and (h) provide written informed consent.

***Participant recruitment.*** Participant recruitment began when a patient voluntary contacted or approached the investigator by phone or on-site for study information. The investigator provided an overview of the study, and asked three questions:

1. Did you start taking PrEP in the last six months?
2. Do you have sex with men?
3. Are you at least 18 years of age?

If the participant answered “no” to any of the questions then they did not meet the study’s criteria. If the participant answered “yes” to all questions, the investigator made an appointment with the patient. The participant was instructed that during this appointment the informed consent and study requirements will be reviewed. Additionally, the participant was told to bring their PrEP prescription bottle to validate they were taking PrEP. Participants were encouraged to ask any questions pertaining to the study. The investigator told the participant to allot for two hours, as after the consenting process concluded, the interview began. Although this did not occur in this study, participants had the option to separate the consenting and interview

processes. In that event, the initial appointment was anticipated to last up to an hour to conduct the informed consent process only.

The investigator and participant discussed potential dates, times, and locations for this meeting. The investigator was aware that depending on space and availability, utilizing the clinic to meet with participants was not be feasible or guaranteed. Therefore, the investigator proposed a secondary interview location, offering participant anonymity and confidentiality. A public library, office, or conference room with a closed door offered the necessary privacy and anonymity for participants. Due to safety concerns, if a mutual location and time could not be agreed upon, the investigator declined pursuing any further research activities with the participant.

During the initial appointment, the investigator determined the patient's eligibility. First, the participants confirmed they (a) were assigned a sex of male at birth; (b) were 18 years of age or older; (c) engaged in AI with men; (d) were currently taking PrEP; (e) began taking PrEP in the past six months; (f) were HIV-negative; and (g) could read, speak, understand, and write English. To verify the participant's PrEP status, the investigator looked at the prescription bottle verifying that Truvada was dispensed to the consenting participant within the past month. Second, the investigator detailed the study requirements: (a) informed consent, (b) one 60-minute audio recorded interview, and (c) completion of a demographic form. Participants were informed that after completing the interview and demographic form they would be compensated with a \$30 Visa® credit gift card for their time. The investigator detailed the steps taken to protect their confidentiality, and clarified any study related questions. Lastly, the investigator reiterated that participation was voluntary, as consent could be withdrawn at any time without penalty, and had no impact on care or services receiving at the current or any PrEP location. If

the participant agreed to the research procedural terms, the participant underwent the informed consent process.

### **Informed Consent**

Each eligible and willing participant underwent informed consent. The participant was given the most currently approved consent form (see Appendix J), which detailed the study purpose and procedures, and the investigator read and reviewed the form with the participant. All study questions were answered at that time and at any point during study enrollment. For participants unwilling to provide consent, the investigator discontinued all study procedures with the participant. In the future, if the participant wished to be a part of the study, they would have to contact the investigator. Consenting participants provided their legal signature in the indicated areas on two copies of the most current and approved consent form. The investigator likewise signed in the appropriate places on both copies. The investigator and participant each kept one of the signed consent forms to keep for their records. The research participant had the right to withdraw their consent verbally at any time during study enrollment.

### **Researcher-participant Relationship**

Trust, respect, and empathy are actions believed to establish rapport with the participant, so that the participant can be authentic during the interviews (Dang, Westbrook, Njue, & Giordano, 2017). A neutral relationship and rapport tactics allow participants to not feel judged by their answers, or respond in a manner perceived to be pleasing to the investigator (Dang et al., 2017); therefore, the investigator maintained a neutral and impartial stance and relationship with participants. Additionally, the investigator built rapport by completing agreed upon tasks (i.e., return phone calls, timeliness of appointments and meetings), being open and honest in

answering participants' questions, and respecting participants' choices (i.e., study participation, sexual behaviors, PrEP initiation, and information uncovered during interviews).

### **Study Enrollment**

Once written consent was attained, the participant was enrolled in the study. The investigator completed the Study Enrollment Form (see Appendix K), which documented the participant's eligibility. The participant was assigned a PID number, beginning with PID-001, and was provided or assigned a pseudonym.

### **Research Instruments**

In qualitative research, the primary research tool is the interviewer (Creswell, 2013), but participants dominated the discussion, with the investigator guiding the interview. The investigator followed the six-item interview guide (see Appendix L), asking probing questions to gather more information or gain more clarity regarding the responses. The demographic form (see Appendix M) was completed by the participant at the end of the interview which collected the participants' age, race, ethnicity, annual income, PrEP start date, AI behaviors, number of sexual partners in the previous 3 months, and condom-use percentage. The interview guide and demographic form were specifically developed for this study. Although this weakens the validity and reliability of the tool, the theoretical framework was used to construct the guide. Immediately after completing the interview, the investigator took field notes, documenting participants' nonverbal and/or emotional behaviors.

### **Conducting Interviews**

Participant interviews occurred after written consent was obtained. Although this did not occur during this investigation, the investigator devised a contingency plan for patients wishing to separate the consenting and interviewing processes. In those circumstances, the investigator

would have scheduled the interview immediately after the patient provided written informed consent. When scheduling the interviews, the investigator would have utilized the same procedures identified in the initial appointment procedure. Conducting participant interviews in the same location as the initial appointment would have been encouraged, but not guaranteed.

***Pre-interview procedures.*** Prior to each interview, the investigator self-identified all assumptions and biases related to MSM and PrEP. These self-identified assumptions were written down and bracketed. Bracketing is the process of the investigator acknowledging personal biases regarding the phenomenon and clarifying how those biases can influence and misconstrue the interpretation of the participants' interviews (Toles & Barroso, 2014b). For this study, the investigator identified and reported personal feelings, beliefs, and experiences pertaining to PrEP and MSM. Twenty-four to 48 hours before meeting with a participant, the interviewer confirmed the interview location, date, and time with the participant. The investigator documented the confirmation or any changes to the agreed upon plans on the study participant's enrollment form. This allowed time to prepare for the interview, and ensured the setting still met the anonymity and confidentiality requirements.

***Interview procedures.*** During the interview, the investigator followed the six-item interview guide. The interviewer had bottled water and tissues on site for participants' use. Additionally, the interviewer utilized two audio recording devices during the interviews.

***Post-interview procedures.*** Post-interview, there were requirements for both participants and the investigator. Participants completed the demographic form, and the investigator gave the participant a \$30 Visa® credit gift card. Each participant acknowledged receiving compensation at that time by completing the indicated area on the demographic form. Once completed, the participant was un-enrolled from the study. The investigator took field notes, to capture

participants' nonverbal and/or emotional behaviors they exhibited during the interview. Post-interview, journaling is encouraged as it allows the investigator to bracket biases before conducting additional interviews (Toles & Barroso, 2014b). Therefore, the investigator also set aside time for reflective journaling to identify personal biases about participants' responses.

### **Data Analysis**

*Descriptive statistics.* Descriptive statistics only described the sample's demographics, as no inferences were based on this information. Specifically, means were used to describe the sample's age, number of sex partners, and condom-use rate, while percentages described ethnicity, race, annual income, and sexual behaviors.

*Transcribing interviews.* In qualitative studies, data analysis entails the process of transcribing the interview raw data, which determines the study's findings and results (Toles & Barroso, 2014a, 2014b). The investigator used the paid transcription services of Rev.com, <https://www.rev.com/>, to have the audio recordings from the interviews transcribed verbatim. The interviews were submitted for transcription within 24 hours of completing the interview. After receiving the transcript, the investigator performed a transcript audit while listening to the interview within 48 hours of receiving the transcribed interview to verify the transcript's accuracy.

*Inductive content analysis.* After verifying the transcript's accuracy, the data was analyzed using a content analysis approach. Content analysis is used commonly in qualitative description studies (Neergaard et al., 2009; Sandelowski, 2000; Vaismoradi, Turunen, & Bondas, 2013). The purpose of content analysis is to analyze text to describe its characteristics "by examining who says what, to whom, and with what effect" (Vaismoradi et al., 2013, p. 400). The findings of the content analysis reveal "a true insider perspective", that adds to the study's

credibility (Neergaard et al., 2009, p. 4). An inductive approach was warranted due to the absence of previous research pertaining to the phenomenon (Elo & Kyngas, 2008).

This investigator followed the inductive content analysis process of Elo and Kyngas (2008) (see Appendix N), which encompasses three phases: preparation, organizing, and reporting. In the preparation stage, the interviewer thoroughly and carefully read the transcribed interviews and acquired an understanding of the main ideas. From the main ideas, the investigator selected themes that emerged regarding this sample's PrEP initiation decision-making process. The investigator then asked who, what, when, where, and why regarding the content. The investigator organized the themes through open coding, as she wrote notes and headings that described the content, and this process was repeated multiple times. The headings were transferred to coding sheets that were grouped into broader abstract categories.

The investigator used peer checking to verify the accuracy of the analysis. Peer checking involves the use of an external colleague or committee to validate the investigator's findings and conclusions (Colorafi & Evans, 2016; Houghton et al., 2013; Neergaard et al., 2009). The investigator had an assembled four-member research oversight committee, but peer checking occurred with the committee chairperson. The investigator submitted the content analysis results electronically (i.e., email) of the first two interviews to the chairperson within 24 hours of completing the analysis of the second interview. The chairperson provided feedback within five to seven business days. Once the chairperson believed the investigator was analyzing the data competently, or to their standards, the analysis results were then submitted to the committee chairperson after analysis completion of every fourth interview. This collaboration ensured that the investigator's analyses were evaluated and confirmed by an experienced qualitative researcher. As more interviews were collected that allowed more understanding, the investigator



had to revert to the preparation and organizing phases. Lastly, in reporting and disseminating the study findings, the investigator detailed the content analysis process, explained the connection between the data and concluded results, and used actual participant phrases and statements to demonstrate authenticity.

Interviews were ongoing until data saturation of the themes representing MSM's PrEP decision-making process was reached. Data saturation is "the point in the data collection process when no new concept-relevant information is being elicited" (Kerr, Nixon, & Wild, 2010, p. 271). After data analysis reflected that data saturation had been reached, the investigator conducted two more interviews to ensure no new concepts were missed. At this point, the study closed to recruitment. The investigator informed the participating PrEP clinics of the study's closure to participant accrual, and requested that they discard any remaining recruitment materials.

### **Trustworthiness**

Trustworthiness is the reliability of study findings based upon the consistency and appropriateness of research procedures (Colorafi & Evans, 2016; Toles & Barroso, 2014b). Criticality improves rigor and trustworthiness, as it is the thought process leading to research decisions and procedures (Neergaard et al., 2009), and the investigator was critical in conducting research procedures. Trustworthiness occurred on a continuum, requiring the investigator to remain objective, neutral, and consistent in performing research procedures throughout the investigation (Colorafi & Evans, 2016; Neergaard et al., 2009).

The most appropriate methodology was selected given the study's question, purpose, literature review findings, and theoretical framework, which increased the trustworthiness of the study's results (Fulton & Krainovich, 2014). Currently the literature lacks evidence of MSM's

PrEP initiation decision-making, and qualitative description was the best method, as the study objectives were to gather and identify aspects of the phenomenon. Qualitative description is a naturalistic research approach, which allows investigators to gather information based on the sampled populations' human experiences, which are shaped by each individual's personal, social, and environmental factors (Creswell, 2013; Frey et al., 1999; Willis et al., 2016). In developing the interview guide, the investigator used the definitions and concepts of the study's theoretical framework, the IMB skills model. Utilizing the study's theory to design study instruments increased rigor and study trustworthiness, as it demonstrated the research to be theory driven (Stewart & Klein, 2016).

All study procedures were consistent and clearly identified prior to study conduction, which contributed to this study's trustworthiness. The identified recruitment and consenting procedures were followed for each participant. Trustworthiness was established by asking open-ended questions that allowed participants to speak freely telling their story unimpeded (Colorafi & Evans, 2016). During interviews, the interviewer did not interject thoughts, or finish participants' sentences or thoughts. These procedures ensured that the data collected was context-rich with the truth as seen and perceived by the participant (Colorafi & Evans, 2016; Neergaard et al., 2009).

Trust in the data analysis process required the methods used in evaluating the data to follow a consistent and logical pattern and approach (Colorafi & Evans, 2016; Toles & Barroso, 2014b). Following the pre-identified inductive content analysis process, which explains the coding process also increased credibility of the findings (Colorafi & Evans, 2016). Additionally, the investigator instituted journaling and bracketing to maintain the investigation's objectivity and transparency. Journaling and bracketing allowed the investigator to recognize and

acknowledge biases, increasing trustworthiness, as the interviewer did not distort the emic view (Toles & Barroso, 2014b).

Another method to maintain trustworthiness was confirmability, which is the process for evaluating and verifying the results from the study's data analysis (Neergaard et al., 2009). The investigator utilized peer checking to accomplish confirmability, verifying the accuracy and credibility of the transcribed interviews and content analysis results, respectfully (Colorafi & Evans, 2016; Houghton et al., 2013; Neergaard et al., 2009). Adhering to these qualitative traditions, data analysis and collection occurred simultaneously (Colorafi & Evans, 2016). Additionally, the investigator reported findings using actual participants' phrases and statements to link data to the results (Elo & Kygnas, 2008). This upholds authenticity and credibility, as participants' voices were heard (Neergaard et al., 2009). The investigator was the only researcher conducting this process, which built trustworthiness and the credibility of the findings as there was no variance in how the interviews were conducted, reviewed, and interpreted (Colorafi & Evans, 2016; Toles & Barroso, 2014b).

The investigator was well equipped and knowledgeable to function as the principal investigator for this study. She had previous experience as a research coordinator in several medical and health-care specialties including HIV/AIDS. Due to her clinical research experience, she was knowledgeable and familiar in research regulations and principles. She shadowed in different PrEP clinics to further understand the population served and the clinic flow and process. Additionally, her passion and commitment to advancing the knowledge regarding HIV prevention reaffirmed that she had the capacity to conduct this study with the appropriate research integrity.

### **Summary**

This study was conducted following Sandelowski's qualitative descriptive research approach. The absence of evidence regarding MSM's PrEP initiation decision-making and the individualistic phenomenon of decision-making made a qualitative descriptive approach befitting. Qualitative description is appropriate when investigations are conducted to explore individual's authentic experiences, as a way to seek to gather, understand, human experiences from the perspectives of the actual source (Colorafi & Evans, 2016; Neergaard et al., 2009; Polit & Beck, 2012; Sandelowski, 2000, 2010; Willis et al., 2016). The study's implications are consistent with this naturalistic research methodology, as qualitative studies are indicated for developing tools and interventions for clinical practice (Toles & Barroso, 2014b). From this study, health professionals will know what this sample of MSM understood about HIV and PrEP, which can be used to identify opportunities to assist current and future patients in resolving occurrences of uncertainties and misconceptions about PrEP and HIV.

The investigator identified PrEP providing clinics in the states of Alabama and Georgia first and later expanded to other clinics in the Southern U.S. Practices agreeing to support the investigator's study were sent IRB approved recruitment handouts and posters to make available to their patients. Interested participants had to voluntarily contact the investigator to express interest in study participation. For those patients, the investigator reviewed the study criteria and requirements in depth, and if the patient had no uncertainties or objections, they were provided informed consent. Audio-recorded one-on-one interviews was the method for collecting data, and the investigator used the study specific and theory-derived six-item interview guide. The investigator utilized a paid transcription service to have interviews transcribed verbatim, and interviews were on-going until data saturation was achieved. At that point, the investigator

conducted two more interviews to ensure no emerging themes were missed. The investigator projected the sample size to be 10-30 participants.

To ensure the study findings were deemed rigorous, the investigator instituted certain procedures and parameters to ensure trustworthiness. The investigator was critical in making research decisions, and remained objective throughout the investigation. Given the study's question, purpose, literature review findings, and theoretical framework, the most appropriate methodology, qualitative description, was selected for conducting this study. The investigator followed all study procedures consistently according to the predefined procedures. The interview guide was developed using the definitions and concepts of the study's theoretical framework, and contained open-ended questions that allow participants to speak freely unimpeded. During data analysis, the investigator compiled appropriate descriptive statistics to summarize the sample, and followed the three-phase inductive content analysis process of Elo and Kyngas (2008) to analyze and identify the common themes describing the phenomenon. The investigator performed reflective journaling and bracketing to identify biases and assumptions regarding PrEP and MSM. In disseminating study findings, the investigator used actual participants' phrases and statements to ensure participants' voices were heard (Neergaard et al., 2009). Lastly, the investigator reported that these findings cannot be transferred to the larger MSM population, and are relative to this sample and possibly of MSM PrEP patients with similar demographics and circumstances.

During this study, the identities of study participants was protected and remained confidential. The researcher adhered to KSU's IRB and participating PrEP clinics' guidelines. Data collection occurred after participants gave voluntary written informed consent, at which point the participant were assigned a PID and pseudonym. Upon the completion of study related

documents, the investigator scanned and saved them onto a password protected and encrypted thumb drive. The hardcopy forms were kept locked and maintained in the investigator's office. This information will remain secured in the investigator's locked office three years post-study closure or according to KSU's IRB's guidelines. Once the span of time has expired, all study related materials will be discarded according to KSU's guidelines.

#### Chapter 4: Findings

HIV pre-exposure prophylaxis (PrEP) initiation decision-making process is relatively unknown. The purpose of this study was to explore this phenomenon in HIV-negative men who have sex with men (MSM) engaging in protected or unprotected anal intercourse (AI). Therefore, the following research question was proposed: How do HIV-negative MSM, engaging in protected or unprotected AI, decide to initiate PrEP? Study objective was to explore how this population decided to initiate PrEP based on the evaluation and perceptions pertaining to their: (a) PrEP knowledge and HIV risk(s)/concern(s); (b) personal and social motivations to initiate PrEP; and (c) behavioral skills and abilities to adhere to PrEP.

This chapter details the findings from this study's data analysis. The investigator used descriptive statistics to summarize the sample's demographics, and described the themes that emerged from participants' semi-structured interviews. Referring to participants by their pseudonyms, the investigator quoted phrases and statements to link and define relationships between these themes. Through open coding, the themes were organized into five broader categories: HIV-risk acknowledgement, HIV concern, PrEP understanding, PrEP accessibility, and PrEP consideration, and the investigator detailed these categories to be the major concepts in a conceptual model detailing this sample's PrEP initiation decision-making process.

Participant recruitment occurred between March and August of 2018. Although the investigator contacted 16 known PrEP clinics in Alabama, Georgia, Louisiana, Florida, and Mississippi, eight responded in agreeing to receive and post IRB approved study recruitment materials in their clinics. Appendix O provides a list of those participating PrEP clinics. Fourteen participants consented, enrolled, and completed the study requirements. This predominantly African American sample (10/14, 71%) ranged in age from 20-59 years, with a mean age of 34 years. Fifty-seven percent (8/14) of the sample completed some form of post-

secondary education, and most participants had an annual income of either less than \$20,000 (6/14, 43%) or between \$20,001 and \$40,000 (5/14, 36%). Table 1 provides the demographic information for each participant.

Table 1

*Participant Demographic Data*

<b>PID*</b>	<b>Age</b>	<b>Ethnicity</b>	<b>Race</b>	<b>Education**</b>	<b>Annual Income</b>
001	28	Non-Hispanic	African-American	High school	<\$20,000
002	33	Non-Hispanic	White	College	\$40,001- \$60,000
003	21	Non-Hispanic	African-American	College	\$20,001- \$40,000
004	49	Non-Hispanic	White	Graduate school	>\$80,000
005	31	Non-Hispanic	White	College	\$20,001- \$40,000
006	33	Non-Hispanic	African-American	High school	<\$20,000
007	27	Non-Hispanic	African-American	High school	<\$20,000
008	49	Non-Hispanic	African-American	High school	<\$20,000
009	30	Non-Hispanic	African-American	High school	<\$20,000
010	51	Non-Hispanic	African-American	College	\$20,001- \$40,000
011	48	Non-Hispanic	African-American	College	\$20,001- \$40,000
012	33	Non-Hispanic	African-American	College	\$40,001- \$60,000
013	20	Non-Hispanic	Other	College	\$20,001- \$40,000
014	24	Non-Hispanic	African-American	High school	<\$20,000
* Participant Identification Number					
** Highest level of education completed					

**Emerging Themes**

Application of Elo and Kyngas' (2008) three phase inductive content analysis (see Appendix N) revealed several themes to emerge regarding this sample's PrEP initiation decision-making process. The interviewer thoroughly, carefully, and repeatedly read the transcribed interviews and acquired an understanding of the main ideas. The investigator selected a theme, being either a word or a phrase that best described the main ideas. Themes regarding PrEP knowledge were revealed to be perceptions and understanding of PrEP's indications, benefits,



risks, and consequences. HIV risks and concern themes included susceptibility from risky behaviors and factors, deception/lack of disclosure, and HIV/sexually transmitted infection/disease (STI/STD) exposure scares. Additionally, this sample's HIV concern encompassed both physiological fears and social implications from contracting the virus. Although social motivations were not apparent in this data, personal motivations were revealed to be added protection and peace-of-mind that initiating PrEP provided. Cost and availability of services were the themes associated with the sample's behavioral skills and abilities to adhere to PrEP. The data demonstrated these themes were weighed and evaluated, leading to their decision to initiate PrEP. The investigator analyzed the transcribed interviews to assess and understand how the identified themes were rationalized as factors a part of this sample's PrEP initiation decision-making processes. From that analysis, five broader and more abstract categories: HIV-risk acknowledgement, HIV concern, PrEP understanding, PrEP accessibility, and PrEP consideration were revealed to detail this sample's PrEP initiation decision-making process. The investigator's process for discovering these five categories are discussed below.

### **HIV-risk Acknowledgment**

Participants were asked about their perceived HIV risks, and each openly admitted to knowing the behaviors and factors placing them at HIV risk. Table 2 lists the overall HIV-risk behaviors and factors reported by the sample, and Table 3 summarizes the sample's reported sexual and AI activities in the previous three months.

Table 2

*Participants' Overall Reported HIV-risk Behaviors & Factors*

# Participants Reporting	Behaviors & Factors
14	HIV status deception/ lack of disclosure
10	Multiple sex partners
10	Inconsistent/no condom use
6	Open/casual/impulsive sex
5	HIV MSM disparity
4	Sex with partner with an unknown HIV status
2	Sex with partner with HIV
2	Sex with partner with an STI
3	Engaging in sex
3	Condom failures (breaks)
2	Having sex cognitively impaired
2	HIV prevalence (geographic region)
1	Threat of physical violence or sexual assault

Table 3

*Participants' Reported AI & Sexual Behaviors\**

PID	# of Sexual Partners	Condom-use Percentage	Anal sex (insertive) Yes = Y No = N	Anal sex (receptive) Yes = Y No = N	Oral sex (give) Yes = Y No = N	Oral sex (receptive) Yes = Y No = N
001	30	75	Y	N	N	N
002	8	20	Y	Y	Y	Y
003	10	0	Y	N	Y	Y
004	5	0	Y	Y	Y	Y
005	4	0	Y	Y	Y	Y
006	1	50	Y	N	N	Y
007	0	--	--	--	--	--
008	2	100	Y	N	N	N
009	4	100	N	Y	Y	Y
010	0	--	--	--	--	--
011	3	90	N	Y	N	N
012	3	100	Y	N	Y	N
013	3	25	Y	Y	Y	Y
014	8	80	Y	N	Y	Y

\*Refers to behaviors that occurred in the previous 3 months

As Tables 2 and 3 indicate, this sample admitted to engaging in several sexual behaviors placing them at risk for HIV. The most commonly reported HIV-risk behaviors were having multiple sex partners, using condoms inconsistently or not at all, and engaging in open/casual/impulsive sex. The responses indicated that these behaviors were the norm for this sample prior to initiating PrEP; however, the study did have an outlier. One participant reported that due to the availability of PrEP, he deliberately changed his sexual behaviors, increasing his HIV risks for the purpose of initiating PrEP. Dan, age 49 described,

I had one long-term relationship from the age of 18 to 25 in college. [So for] seven years, [I was with] one person. Uh, 25 to 47 [I had] one relationship, monogamous, [and] I've only recently branched out, because I honestly feel like I missed out on a lot of sexual exploration in my youth that I wish to make up lost time, and PrEP seemed like the only logical way to do that.

Without PrEP, Dan said, "I would not be putting myself out there with multiple people. No, I would not." Acknowledging the risks accompanied by this new behavior, prompted Dan's initiation of PrEP.

Although sexual behaviors were significant HIV risk factors, as Table 2 indicates, HIV deception was the most commonly non-behavioral perceived HIV risk factor. HIV deception was discovered to be the deliberate act of a person with a known HIV-positive status lying about or withholding their positive status from their partner prior to a sexual encounter. Ace commented, "I've learned a lot of people don't disclose themselves," and Beyonce echoed this sentiment stating,

No one will tell the truth when you ask. I mean you be sitting there having a general conversation with someone, and y'all are discussing sex things. Okay, well if it's

comfortable enough for us to discuss sex, we should be comfortable enough to discuss our status. And, for some odd reason, a lot of them don't like to discuss their status.

Participants conveyed and shared their personal experiences regarding peers being actually deceived by an HIV-positive partner. Participants did not have to experience or be personally involved in HIV deception in order to perceive it as a risk factor, as participants repeatedly voiced HIV deception as an HIV risk from listening and hearing stories from peers. Bruce reiterated, "Yeah, they're gonna lie, and I find that too often. And I know people be deceptive and try to get what they want." Participants believed that deception is done maliciously as Steve said he has heard "horror stories of men purposely infecting others." Dre further explained his experience, "I've encountered people who just don't give a fuck, and they're just like, 'Well I've got it, and nobody told me that they had it. So I'm just gonna give it [to] somebody else.'" Beyonce shared his story of learning about his best friend contracting HIV due to deception, and that experience was key to his decision to initiate PrEP as he stated, "When I found out my best friend was HIV positive, I knew right then I needed to do something. Because if you can be with a man that says he loves you, and yet, he basically took your life from you, then, I mean, what makes me different from [him]?" Today, HIV deception is perceived to be easier, due to the advances in HIV care and treatment, as PLWH look no different from those who are HIV-negative. Percy confirmed this perception from his experience with a former partner who was positive, "He looks very nice, like you wouldn't even [have thought he was positive]. HIV doesn't have a face or anything."

The impact on acknowledging HIV deception and the lack of disclosure was seen by this sample to significantly increase HIV risk and was a factor in their decision to initiate PrEP. Ace declared, "On a scale of 1 to 10, I would say 10, [with] 10 being the greatest," and Alex admitted

that concerns about HIV deception “was like one of the major factors [be]cause you can trust somebody but you're never 100% sure.” The ease and frequency in which this sample perceived HIV deception to occur created a sense of distrust in potential or current sexual partners.

Participants, Dan and Poomp blatantly expressed that it is difficult to trust and take people at their word, as Dan said, “people will lie to your face“, while Poomp responded that, “[you] just can't believe them or trust them”. Even Bishop commented that “it's kind of hard to trust anything with anybody now,” and Dre said, “There are so many people lying about their status and stuff.” Additionally, participants voiced that lies are told regardless of the relationship type or affection a partner can honestly have for the other. Beyonce detailed his experience of a friend contacting HIV after being deceived by a partner

Even if you with a person that says they love you, no matter what, you still can't trust them, not these days. Because this guy sle[pt] beside you every night, and sa[id] he loves you, and he cares about you, but when you asked him, what was his status, he sat there and blatantly lied to you, and said that he was negative, knowing that he was positive. And now you have to live with this.

That acknowledgement of deception and distrust created a heightened sense of fear and concern. Jay expressed, “I'm just afraid, right now. There [are] so many people [out] here just telling you, ‘They ain't got this, and I know my status.’ I don't believe that anymore.”

Additionally, participants did not feel they had a way to confirm a partner's status, as Dre responded, “I don't really fuck with positive guys, but you don't really know who's really what here, because a lot of people aren't telling a lot of things.” That inability to truly know or verify a person's HIV status was concerning, which was rationalized as a reason to initiate PrEP since they believed people to be dishonest and deceptive regarding their actual HIV status. PrEP

provided added protection from contracting HIV, as Bill explained that he tried “to take somebody at their word, but sometimes that's just not enough.” In a similar way, Alex described, “Somebody can tell you, ‘Oh yeah, I'm fine.’ They can even show you their paperwork and everything. You still don't know 100%. People lie, and they can really, really deceive you, so it's best to keep yourself covered and checked.”

STI or HIV scares and experiences were also commonly recognized as an HIV risk factor encouraging this sample's decision to initiate PrEP. Justin and Bishop both expressed an STI scare convinced them of their HIV risk. In these instances, participants had known about PrEP before the exposure scare, as Justin admitted that he “thought about the pill [PrEP] months before,” but did not perceive initiating PrEP to be necessary. The threat of contracting an STI made the threat of HIV real and apparent. Bishop recalled his exposure scare to influence his decision to initiate PrEP, “I had been hearing a lot about PrEP anyhow [and] I didn't really think nothing of it at that time then. Then after I got intimate with this guy and I realized the condom had popped then, I was like, “Yeah maybe it's a sign you need to go ahead and take PrEP”. Alex experienced an HIV exposure scare, triggering his decision to initiate PrEP. After having a protected sexual encounter, Alex became sick, and he immediately thought he had contracted the virus. Regarding that feeling of thinking he contracted HIV he said, “I'd never been that nervous or scared. Even though during that encounter, I was safe, but I still was like, 'Okay, this doesn't feel right.' And I was to the point where like, you know what, I don't want this to happen again. I don't like this feeling.” On the other hand, Dre actually contracted gonorrhea and detailed that experience to prompt his decision to initiate PrEP, as he thought, “You know what? Let me go ahead and give it a try. . . If I can easily catch a STD like that [then] I can easily catch something else.”

When asked to explain the impact their perceived HIV risks including sexual behaviors and factors had on the decision to initiate PrEP, all participants verbalized that these experiences or encounters made the threat of contracting HIV real and probable. That particular threat made them acknowledge their HIV risks, and was a catalyst for making them believe initiating PrEP was necessary given their risks. Dre stated

I'm at risk, you know? Very much so at risk. And I feel like I'm just always a step away from being the people that [are HIV positive]. I don't look down on positive people or anything like that, it's just I could become that. So let me take the steps now to not become that. Like another statistic.

This data thus showed that in this sample's PrEP decision-making process, HIV-risk acknowledgement was a part of the process. For this sample, the acknowledgement came in the person's own time, based on their own perception and understanding of HIV. Additionally, the acknowledgment resulted from a self-assessment of how much the individual believed they were at risk for contracting HIV. Due to acknowledging his HIV-risks, Dre initiated PrEP as "an extra precautionary step". He went on to explain his decision-making:

I was tired of having sex when condoms break or slip off, tired of people lying about their status, tired of running into people who were positive. That's a lot. And I finally was like, "You know what I definitely need to go ahead and get on this". . . I'm sexually active, I'm grown, so I need to be an adult about [it].

Bill initiated PrEP based on his acknowledged HIV risks by stating, "I know me, and I know how much I hook up," and Bruce responded that "I just thought it was just a wonderful thing to do as a preventative measure, [be]cause I'm gonna have sex." Without acknowledging their HIV-risks, the act of considering and initiating PrEP was unnecessary, because the individual

perceived the threat of HIV to be absent, extremely low, or insignificant. Due to their recognized risks, PrEP was viewed as a proactive approach to HIV prevention, as Ace stated, “Just in case I come across someone that is positive, I don't wanna be trying, I wanna prevent from getting HIV”. Participants were driven to remain negative as Dre reiterated, “I'm not going to become one of yall [an HIV positive person] . . . I'm not going to let it [HIV] take me. I'm not going to become another statistic, and PrEP keeps me from becoming another statistic.”

### **HIV Concern**

Participants were asked about their perception regarding HIV. Due to the advances in HIV care and treatment, this sample recognized the disease is manageable and a chronic disease, as PLWH on treatment can live a normal life. Ace stated, “I look at it as any other thing, like diabetes and cancer”. Bill speculated that contracting HIV is “something that you can manage.” Despite this optimal perspective, participants still viewed HIV negatively, as Dan expressed, “My first instinct is, 'Ew, gross', and then my second reaction is sympathy.” This sample continuously described HIV to be a devastating disease, inflicting mental and physical hardships. Bill recalled HIV-positive peers to discuss having “episodes [when they] don't feel good because of [their] status,” and Justin thought that HIV “shortens your lifespan.” For this sample, HIV has not escaped its deadly history. HIV's morbidity and mortality of the 1980s is unforgettable, as Jeff recalled an HIV-positive friend dying from Cryptosporidium to be a “pretty gruesome death,” as he described his friend to have “really suffered.” Logically, participants recognized HIV to be a chronic disease, but it is challenging to be fearless of HIV. Therefore, there is a conflict between present day's HIV and HIV of the 1980s. Additionally, the data indicated that HIV is placed on a higher pedestal than other STIs due to HIV's mortality and incurability. Percy explained that the treatment regimen for other STIs is more favorable or easier to deal



with, as “you can take a pill, get a shot in your butt, boom, [and it goes] away. HIV, they ain't got no cure for that yet.” Steve explicitly explained HIV’s distinction and separateness from other STIs by stating,

In our heads, when it comes to HIV, limiting your exposure to that [is priority, because] the rest of that stuff seems treatable. HIV is the king of king’s disease when it comes to STIs. That is the number one [STI], and of course, we are from a generation that we weren't necessarily around when HIV was definitely a practical genocide of gay men . . . And now, yes, it is treatable, and people consider it under control, but I was just always taught [that] it's not a disease to fear, but [to] have a fearful respect of, it's something you shouldn't fuck around with.

Participants were then asked about their perception regarding the impact HIV has on the lives of PLWH. Consistent with this sample’s HIV fears, they expressed that HIV significantly and negatively affects the lives of that population. HIV was viewed as a life altering, devastating, and changing disease. Percy speculated his reaction if he ever contracted the virus: “I feel like that would like break my self-esteem. I feel like mentally I would be like everywhere, emotionally I'd be broke down. I used to tell myself that I would probably have committed suicide.” Dre expressed similar feelings and reaction about receiving a positive diagnosis as he stated,

Oh my lord, I've thought about that so many times. Yeah, I'm always just on edge. It would be a whole 360 for me. So much stuff would change, honestly. I would still have a life, but I would feel like I fucked myself over . . . I would really feel bad about [it, and], I would be down on myself if I was to become positive. I would feel like I fucked myself over.

The devastation arises from the social implications from contracting HIV, as HIV's social consequences were perceived as more feared and damaging than the physical impact of living with HIV. Repeatedly, participants described PLWH to experience depression, discrimination, judgment, and abandonment from peers and family; however, participants viewed the most significant change from contracting HIV to be within the context of romantic and sexual relationships. Dre commented that PLWH are stigmatized and can be "seen as damaged goods," and he actually emulates that perception, as he refuses to date someone positive stating, "I'm not interested in getting to know you [an HIV positive person]. It's just, no." Bill admitted to hearing PLWH state: "You know if I wasn't positive, this [dating/romantic] situation might have been different." The perception from this sample is that PLWH face and experience rejection routinely due to their status. Jay stated that for those PLWH that have been honest and upfront with him about their status, have prefaced the disclosure with a statement like "You may not like me anymore, because I'm HIV positive."

Participants were asked to explain the impact their HIV concern had on their PrEP initiation decision-making process. The physical and social consequences of living with HIV was indicated as a driving factor for them to initiate PrEP. PrEP provided added HIV protection to reduce their chances of contracting the disease. Participants were cognizant that it only takes one encounter to contract HIV, and they decided to initiate PrEP to reduce the chances of encountering a lifelong battle with HIV. Alex stated he initiated PrEP, because he did not want to be in the position to say, "This one mistake has changed my life drastically," and Dre believed that "HIV is costly . . . and I'm not even talking about costly as far as money. It's costly for your life." Initiating PrEP was viewed to be rather easy and simple than enduring the life changing alternative, as Dre explained, "I see PrEP like this, I voluntarily take this pill so that I don't have

to take a regular mandatory pill for the rest of my life." Participants did not want to deal with the social challenges associated with being HIV positive, especially in romantic and social situations. Participants sympathized with PLWH having to disclose their positive status to someone they genuinely liked or loved, as Percy stated, "I know it's hard". Percy continued by stating

Right now, I don't have to sit here and give a guy this sob story on how I contracted this [virus], and how they don't have to worry because I'm undetectable, and how I'm taking my medicine. [I'm not] worrying about if he's gonna continue talking to me, or if I'm gonna hear from him after I told him this. You know, like getting involved with somebody. Then you tell them something like that and you really like them, and you trust them with that information, and then they go out and bash your name. Then I'm hearing stuff about me that I told only this person. I don't wanna go through all that.

Although not a part of the decision-making process, the data indicated that the added HIV protection garnered from initiating PrEP initiation changed some participants' sexual encounters. For some participants, the peace of mind from the added protection improved quality and pleasure during sex. Steve said, "It makes you feel a lot more freer. . . Not having that fear, knowing you're protected, it truly opens you up". Three participants' PrEP initiation indicated occurrences of risk compensation, as they changed sexual behaviors, increasing HIV and other sexual risks. The investigator has already reported that Dan initiated PrEP for the purpose of engaging in risky sex, and he admitted to having, "more sexual partners, [with] full exchange of fluids." On the other hand, Bill stated, "[I am] a lot more brave than I used to be . . . I'm more open to meeting up with people and having less conversation and more action with them if that's what they're into. Also, trips out of town, there's bars you can hook up at, and you

have yourself a real good time.” Dre admitted that “being on PrEP has made me a lot more open to raw sex with somebody that I trust.” Only one patient reported that he believed initiating PrEP decreased his sexual libido, as Justin stated that since initiation of PrEP “the [sexual] desire is not there.”

### **PrEP Understanding**

In order to make a decision to initiate PrEP, one has to be aware of the regimen. While not a part of the decision-making process, participants voiced their opinions and concerns about society’s awareness and knowledge of PrEP, and their insight provides context to PrEP initiation decision-making. A few participants believed most people know about PrEP, as Ace gave his perspective saying, “Well it's just that, out of 100 people, I think probably it's a 60% chance that people know;” however, this is not the popular opinion. For the participants who chose to speak about society’s PrEP awareness, most expressed concern, as they perceived there to be a lack of PrEP awareness, especially in MSM and other HIV vulnerable populations. Steve described his experience from finding out about PrEP, “When I learned about it I was like, ‘Wait a minute, I’m sorry. This drug exists?’ And not knowing that it was public knowledge for years, I was like, ‘So this drug exists.’ I don’t know why everyone doesn’t know about this.” In a similar way, Bill detailed that “There’s a lot of people [that] just don’t know. Even in the gay community, [they] don’t know a whole lot about it [PrEP].” Beyonce said some of his previous sexual partners were oblivious to PrEP, as he reported, “A lot of them have been like, ‘What is that?’ And I’m like ‘Oh my goodness.’” Although MSM is an HIV vulnerable population, adolescents and young adults were also identified as an HIV vulnerable group lacking PrEP awareness and knowledge. Jeff stated “I think it should really be pushed towards our younger generations,” and his reasoning

was that “our younger generations are more sexually charged and they are more [likely to] experiment with sex with different partners, with different men, women, [or] alcohol.”

Specific to the decision-making process, participants were asked their initial impressions of PrEP. For this sample, participants learned about PrEP from either one of three entities: health professional (6/14, 43%), peer or partner (3/14, 21%), or social event/advertisement (5/14, 36%). Upon initially learning about PrEP, patients formulated different types of preconceived notions and misconceptions about PrEP. Dre stated, “My feelings of it were very iffy back then,” which “kind of kept me from really getting on it.” Participants experienced moments of disbelief, as they found it difficult to believe that a medication existed for HIV prevention. Some participants initially perceived PrEP to be fake or a placebo pill that does not really work to prevent HIV. Percy said, “I was thinking that it was like a gimmick. I didn't know if it was proven to prevent HIV. I didn't think it would be effective, honestly.” Others initially thought PrEP to be a scheme, presenting users with a false sense of protection that causes them to eventually contract the virus or increases one’s HIV risk. Jeff said, “At first I was like, is it going to lean me towards saying that I’m going to become that way,” while Beyonce thought, “it gon' give me HIV”.

Participants were also confused about PrEP’s clinical indications. Jay said, “I thought it was to cure HIV,” and even Jeff grappled with initiating PrEP, as he stated, “I don't want anyone thinking that I got HIV”. Bill said, “What is confusing to me about it, or at the time was, the medication itself. That it didn't really make sense to me that this was something that you take if you already had it.” Data showed the consequences of these misconceptions to be significant, as Justin commented that “a lot of people look at PrEP, and the way that it's put out in the streets is if you're on PrEP, you have HIV.” Dre reiterated this social perception of PrEP stating there is

“a lot of suspicion, a lot of stigma. . . Like a lot of people think that I'm positive because I'm on PrEP.” The data showed the consequence of this confusion to be continued social misconceptions and negative stigma surrounding PrEP, as Justin explained, “A lot of people run from people that say that they're taking PrEP.” Additionally, those with PrEP interest or indications are deterred from seeking PrEP, as Jeff stated, “People are scared to ask [about PrEP], because people want to know why [are] you asking.” Dre stated that “people either feel like either you're promiscuous if you're on PrEP, or you're lying about your status.” From this sample’s perception, these societal stigmas and misconceptions occur because, PrEP information is not clear in the beginning, as Bill went on to explain that the available PrEP information was “very vague to start with [and] the basic things of it were not so simple.”

Despite participants’ awareness of the social perceptions and stigma about PrEP, social motivations were not apparent in this sample’s PrEP initiation decision-making process. As the data indicated above, participants were cognizant of the stigma surrounding PrEP, but those perceptions and opinions, were not revealed to be directly involved in the decision-making process. Participants did not state that their decision to initiate PrEP to be driven or dependent by the potential reaction of anyone, including peers, partners, or family members. Dre addressed the lack of social motivation in his decision-making process stating, “I don't give a fuck about the stigma. I don't give a fuck about what you've got to say. I feel like we should take advantage of these programs that are here to help us.”

Whether out of confusion or a desire to know more, after learning about PrEP, each participant gathered more information. Participants primarily performed internet searches on PrEP to seek clarifying information. Beyonce said, “Uh, google” was his means for conducting research, as he stated, “I had to go through google.” Similarly, Justin said “I just typed it in [the

search engine] and then I read a small paragraph about it.” Only one participant reported to make his decision from accessing empirical evidence about PrEP’s chemical make-up and efficacy reports, as Dan “did a little bit of research into the biochemistry of it all and made a decision.”

Some participants gathered more information by consulting with a health professional, and the data showed these participants expressed feeling more at-ease and comfortable making their decision. Alex, who worked in a health-care facility discussed it with a pharmacist, as “That's the main person I talked to, was our pharmacist. And she was like okay, these are the benefits to it, but these are the risks.” Steve stated that “sitting down with your doctor that you know and trust, and just breaking it down very simply” was significantly helpful in him making his decision. He continued by stating

I talked to my doctor, and I made him give me a 30 minute breakdown on literally the history of the pill for HIV treatment and then evolving into PrEP. It was incredible to hear, and it was at this time I was like, “I understand.” Somebody sat down and explained the science of it, and the history, and where it came from . . . When something [gets] broken down to you in layman terms, but not shortened to a 30 second commercial, but maybe a four or five minute video, that's what you need.

However, not all available PrEP information from health professionals is accurate. Steve shared his experience of discussing PrEP with his local pharmacist on the length of time it takes before PrEP becomes effective in the body. Steve recalled, “Some said ten days. Some said two to three weeks. Some said 30 days.”

Even though not all PrEP information available is of equal merit and accuracy, participants did express that they came to understand PrEP to be complementary. This sample

acknowledged that PrEP does not create HIV invincibility, and therefore is to be used in conjunction with condoms and other risk-reduction practices, as Jay stated that, “they told me, you still have to use condoms.” Bill thought PrEP to be a magic pill initially, granting him permission to engage in any risk behavior, as he said, “Woohoo, I can do whatever I want now;” however, after gaining more education, Bill realized that PrEP is like any other non-abstinence prevention method, as “nothing [else] is 100 percent” protective against HIV. Ace reiterated this also by stating, “I have to make sure that I continue to [have] safe sex, continuing to use condoms, and taking the PrEP.”

The data indicated that not all misconceptions and ambiguities were resolved prior to initiating PrEP. Bill stated that he was not informed or understood the full implications or requirements of adherence. From his perspective, he was told initially, “Well, here's your bottle, take your medicine.” He did not feel that anyone gave him specific instructions that PrEP “needs to be [taken] the same time every day; you need to take it regularly; [and] don't miss your doses” in order to achieve optimal efficacy and protection. Therefore, participants suggested that having clear and complete instructions and education from health professionals on how PrEP works to be effective, and explaining the reasons behind the follow-up schedule would make things less confusing. According to Steve, the availability of in-depth patient education “just doesn't exist, unless you go out of your way to look for it on YouTube. And You Tube is wrong, I'm sure.”

Initiating PrEP is not without some requirements, and the data showed participants to factor their understanding of those aspects into the decision-making process. PrEP's required daily intake was primarily viewed as an inconvenience, but that inconvenience was not significant enough to deter this sample from initiating PrEP. Jeff said, “Yeah, I was concerned,



but I started thinking, I take high blood pressure medicine every day, and I don't think a second thought about it. It's just natural.” Although not an aspect of the investigated phenomenon, data revealed that despite the inconvenience of the daily regimen, that PrEP adherence improved when it was associated with an activity or entity they performed on a routine basis. Steve stated that a routine “absolutely helps me. It's habit building.” Ace said, “At first it was, [challenging], and then eventually it became like natural. Taking it every day, like a vitamin, because I would put it with my vitamins, so that way I know I would see it every day, so I know to take it.” Beyonce reported that his job was his daily reminder or trigger to take PrEP, “I just think about it as, well, every day when I take the medication, it's time for me to clock in for work. So therefore, I need my job, I need this medicine. I need my job, I need this to stay healthy.”

Initiating PrEP is also associated with side effects, and a few participants had serious concerns about PrEP's side effects. Knowledge of the potential side effects (i.e., nausea, vomiting, kidney issues, and bone density loss) caused a few participants to really question and the need to initiate PrEP, as the side effects were frightening and delayed initiation for some participants. After learning about the side effects, Jay stated, “So then I didn't get on it,” and Percy was deterred from initiating PrEP thinking, “I'm gonna stick to trying to wear condoms.” Although some participants were concerned about the side effects, it did not prevent them from initiating PrEP; however, they identified experiencing side effects would be reason enough to discontinue PrEP. Jeff initiated PrEP with a disclaimer, “I was thinking that as long as I don't have any [side effects] then” he would continue taking PrEP.

Participants were asked to explain the impact their understanding of PrEP had on their decision to initiate PrEP. Ultimately, despite the participants' knowledge or perception of PrEP being accurate or not, participants were satisfied or accepting of their understanding of the

perceived benefits and risks associated with PrEP initiation, as Dre stated, "I said, 'You know what, let's give it a try.'" Although uncertainties regarding how PrEP is efficacious remained, participants admitted to initiating PrEP, because of its indication to reduce HIV risks. That knowledge alone was worth initiation, as Bishop remembered thinking, "I'll just gamble with it," and Poomp also took the trial approach saying, "I just wanted to try it and see if it'd work".

### **PrEP Accessibility**

Participants were asked to explain the means and manner in which they accessed PrEP. The data showed that accessibility encompassed two aspects: cost/financial means and provider availability. In the PrEP initiation decision-making process, participants' abilities to afford the monthly cost of PrEP was a factor. Most participants found accessing PrEP challenging, as participants were aware of PrEP's exorbitant out-of-pocket/cash price. Table 4 provides a list of this sample's reported financial means to accessing PrEP.

Table 4

#### *Participants' Financial Means to Accessing PrEP*

<b># of Participants Utilizing</b>	<b>Financial Accessibility Options</b>
6	Assistance Program*
3	Employer/Private Insurance
2	Employer/Private Insurance & Assistance Program*
1	Clinical Trial/Study
1	State Medicaid
1	Other Personal/family Resource
*Program provided by PrEP clinic and/or Gilead®	

As Table 4 indicates, most participants utilized an assistance program sponsored by either the providing PrEP clinic and/or PrEP's pharmaceutical company, Gilead®. Only one participant, Dre, reported accessing PrEP as a clinical trial research subject. Despite participants having different avenues to covering PrEP's financial cost, repeatedly participants stated that

they would not have been able to initiate PrEP without financial assistance from the program or an insurance company covering most or all of the cost. Since most participants stated that they accessed PrEP through an assistance program at minimal or no cost, this study could not quantify PrEP's monetary value or worth, as this investigation did not inquire about the maximal dollar amount they would be willing to pay for PrEP.

Even participants with private insurance and more affluent salaries placed a value limit on accessing PrEP. In this instance, Dan is an outlier again, as he reported having an annual income greater than \$80,000 and private insurance that covered 100% of PrEP's monthly cost. Although he had more financial resources than any other participant, he admitted that there was a limit to paying for PrEP, as Dan stated, "I'm telling you that I wanted to engage in risky sexual behavior, but I wasn't willing to pay more [than] \$100 a month . . . I wouldn't pay a lot of money to take PrEP, it's not that important to me." Another example is Alex's situation, a health professional with a reported annual income range of \$40,001- \$60,000, but his private insurance declined to cover any cost of PrEP, and only covered a smaller portion of the drug after the drug discount card was applied. He stated, "Initially, my health insurance, [was] like, 'Oh no, no, we're not gonna cover this,' but then with that discount [card], they were like, 'Okay', [be]cause after the discount, it was like \$200 or \$300, and they were like, 'Fine, we'll pay for it.'" Alex confessed that he could not afford to pay \$200 or \$300 a month for PrEP, and as Bill stated, "Even if somebody makes good money, and once your bills are paid, that doesn't leave a whole lot left over for something like that. It'd be cheaper to get sick. I hate to say that, but it almost feels that way." A similar sentiment was echoed by Jeff when he stated, "I feel sorry for the young kids who need it and can't afford it, because they don't have any insurance. You know it's almost like giving them a death sentence, for catching HIV."

The other aspect of PrEP accessibility pertained to the availability of and ability to access PrEP services. Without access via telemedicine or in-person, participants could not initiate PrEP. This sample of MSM PrEP patients mostly lived in urban areas that had available local PrEP clinics and providers. Only one participant, Bill, lived in a rural area where the nearest PrEP clinic was over 150 miles away. Despite the distance, he decided initiating PrEP was worth having to act as his own advocate:

I felt that it was a good option for me, and it was definitely worth kinda the struggle to get a referral. I've had to do all the extra work. I've had to make the phone calls, I've had to do the follow-ups, and stuff like that, whereas in big cities, people are like, 'Oh, I just told so and so, and just got started on it after doing the testing process.' Whereas for me and for other people in these more rural areas it seems like it's a little more of a challenge.

The data did not indicate if all patients would have been willing to go through such challenges and adversities to access the services required to initiate PrEP.

### **PrEP Consideration**

The data indicated that this sample had a period in which they weighed and considered all the available information they had regarding their (1) acknowledged HIV-risks; (2) HIV concerns, (3) PrEP understanding, and (4) PrEP accessibility. Given their self-assessment of their HIV risks, knowledge and understanding about PrEP's benefits and risks, participants explained that initiating PrEP was necessary, as it was thought to offer them peace of mind and added assurance for HIV protection. Bill stated, "I thought PrEP was a really good choice for that, it's just kinda that peace of mind," and Dre said "as long as I'm single . . . and sexually active, I'm going to be on PrEP . . . just as a safe umbrella." Dan said that PrEP allowed him to engage in risky sex "without thinking of the repercussions, without worrying". Likewise, Steve

initiated PrEP to take “a heavy weight off my shoulders.” Lastly, Ace stated, “I just wanted to feel comfortable, just in case I did or I started to get involved with somebody else again, or got to the point where we were having sex. It was a comfortable feeling, that I don't have to be always worried. I just wanted to be comfortable, and PrEP's there to kind of ease up the stress.”

Initiating PrEP was thought to remove guilt and shame from sexual acts, as Bill said, “You don't feel as, ‘Oh my gosh, what did I just do?’ You don't have that immediate guilt following your activities, whatever they might be.” Initiating PrEP was also a way to take control of one's HIV risks before the HIV threat appeared, as it is a proactive approach to HIV prevention. Steve stated, “Inviting new sexual partners into our lives, it is the safer decision . . . And it's like you're taking that big boy responsibility of taking this drug to protect your life.” These participants favorably valued PrEP's benefit from their self-assessment of HIV risks and concerns, PrEP's benefits to risks ration, and PrEP accessibility.

Even in the midst of challenges or uncertainties, the data showed initiating PrEP was considered to be worth those adversities. Bill experienced difficulties finding a PrEP clinic, and the nearest clinic was over 150 miles away from his home. Despite the logistical challenges, Bill stated, “I'm very glad that I did it, it's just not the easiest thing to do right now at this time.”

Additionally, the inconveniences that come with initiating PrEP was accepted, as Steve reiterated, “It is worth your time and money and your patience to get on a medicine that protects you from a life altering disease.” This is especially true considering the occurrences of HIV exposure scares or deception, as initiating PrEP was worth more than experiencing HIV scares. Percy stated, “I ain't fit to be going through these scares, and then worrying about if I'm clean or not.” Initiating PrEP was also perceived as a way to remain HIV-conscious, as Ace described, “It was something that kept me on my toes for one, because you have to take it every day. And

every day you take it is a reminder about HIV.” Lastly, some participants thought taking PrEP was just a logical decision given their susceptibility and perception regarding HIV. Justin said after evaluating all of the factors that “it was really like a no brainer for me,” and Jeff said, “I started thinking, you either want to take this [PrEP] or want to end up becoming positive and taking a lot of medications or being sick.” Additionally, given PrEP’s frequent follow-up and testing regimen, initiating PrEP was viewed as a form of self-accountability regarding their own HIV status, as Ace responded, “PrEP was something I could take, and be aware of my status, and be protected. I could make sure, everything was good. . . I just wanna check myself, before I check somebody else.” After considering all of these factors, the data showed that participants decided to initiate PrEP because that action was viewed to be worth more than not initiating PrEP.

Although not a part of the investigated phenomenon, participants did discuss their PrEP disclosure habits including who and when they had or will disclose that they initiated PrEP. Participants stated that they disclosed their PrEP status to family, peers, or sexual partners, and in most cases, participants reported that the reaction from their disclosure was positive and supportive. Bishop repeated a friend’s response from his PrEP status, “You know I think that's a smart move to make, to take PrEP, to keep yourself secure.” Family members expressed a sigh of relief from their loved-one having additional HIV protection. Beyonce recalled his mom’s reaction, “Thank the Lord, [be]cause she was like, ‘I don't wanna get that phone call,’” that he contracted HIV. In a similar way, Steve stated his mother responded, “Oh, that's nice to hear. You know, there's a lesser chance that my kid will end up saying ‘I'm HIV positive.’” Some participants did not feel the need to disclose to family and friends, as Dan stated, “There's no need for anybody [family or friends] to know that information.” Participants reported that they

most often disclosed their PrEP initiation to sexual partners, and the reaction is one of security, as it provides partners with a sense of relief, affirming their partner is negative. Dan stated, "Well, their reaction is that's good, [be]cause they know you have to be negative to get on it. So that gives them a sense of security," and Dre believed that potential sex partners think that upon hearing he is on PrEP, "Ah, he's clean . . . He's good to go." Although most participants reported a positive response from their PrEP initiation disclosure, the data showed that this was not everyone's experience. The reason for the disapproval was not known or clearly understood by the participants, but the data leads the investigator to assume it pertains to the negative stigma or misconceptions surrounding PrEP. Bishop said he did not have many supporters, as most peers' responded to his disclosure by stating, "You're stupid, I wouldn't take that stuff." Beyonce recalled a peer's reaction from his PrEP status, "I don't know what to say. I just never thought you, out of all people, would decide to take PrEP." Percy explained that he was surprised by the response from a sexual partner,

I don't think he was too happy when I mentioned about being on PrEP. He was not too happy about that. He said, "Oh, what, you gonna be out having sex with random people now?" I said, "Is that what you think PrEP is for?" He was like, "Basically. Like PrEP is for people who just have sex with a lot of people."

### **PrEP Initiation Decision-making (PID) Model**

The data indicated that the decision to initiate PrEP was a process that occurred after learning or becoming aware of PrEP. Although this study's findings could not determine an average or estimated timeframe for this sample to navigate through the process, the data indicated the decision to initiate PrEP was not immediate or made impulsively or frivolously. Instead, deciding to initiate PrEP was discovered to be a thoughtful process of weighing and

considering specific factors regarding HIV and PrEP seriously and meticulously. Percy stated, "It definitely was a process. Definitely... it's not something like, 'Oh, this prevents HIV, let me get on it.' Like it wasn't that." After learning about PrEP, Justin thought, "I have to think about this. This is something that I have to process in my mental," and Dre admitted that "I still had like my reservations. . . I wanted to see how [other people taking PrEP] was progressing along before I jumped into it." From the analysis emerged a conceptual model demonstrating the process determining and influencing this sample's decision to initiate PrEP encompassing the data's five emerging themes: (1) HIV-risk acknowledgment, (2) HIV concern, (3) PrEP understanding, (4) PrEP accessibility, and (5) PrEP consideration.

From the data, conceptual definitions and relationships emerged and are depicted in Figure 3. Acknowledged HIV-risks is the acceptance that certain behaviors or factors place a real and actual threat to the individual for contracting HIV. HIV concern is the negative and fearful perception that living with HIV will have on one's life and well-being. While these two individual concepts do not impact or influence the other, they both impact the decision to initiate PrEP, as a greater belief in one's acknowledged HIV-risks and more HIV concern was revealed to directly influence this sample's decision to initiate PrEP. PrEP understanding is the information, accurate or not, that the individual has about PrEP or conceives PrEP to be, which includes but not exclusive to PrEP's benefits, risks, and indications. PrEP accessibility is the ability to access PrEP both financially and from a prescribing clinical practice. Both PrEP understanding and accessibility are separate entities that influenced and determined this sample's decision to initiate PrEP. Lastly, PrEP consideration is the act of weighing and evaluating the need to initiate PrEP based on the four model concepts. Like the four concepts, the result of their PrEP consideration was shown to influence their decision to initiate PrEP.



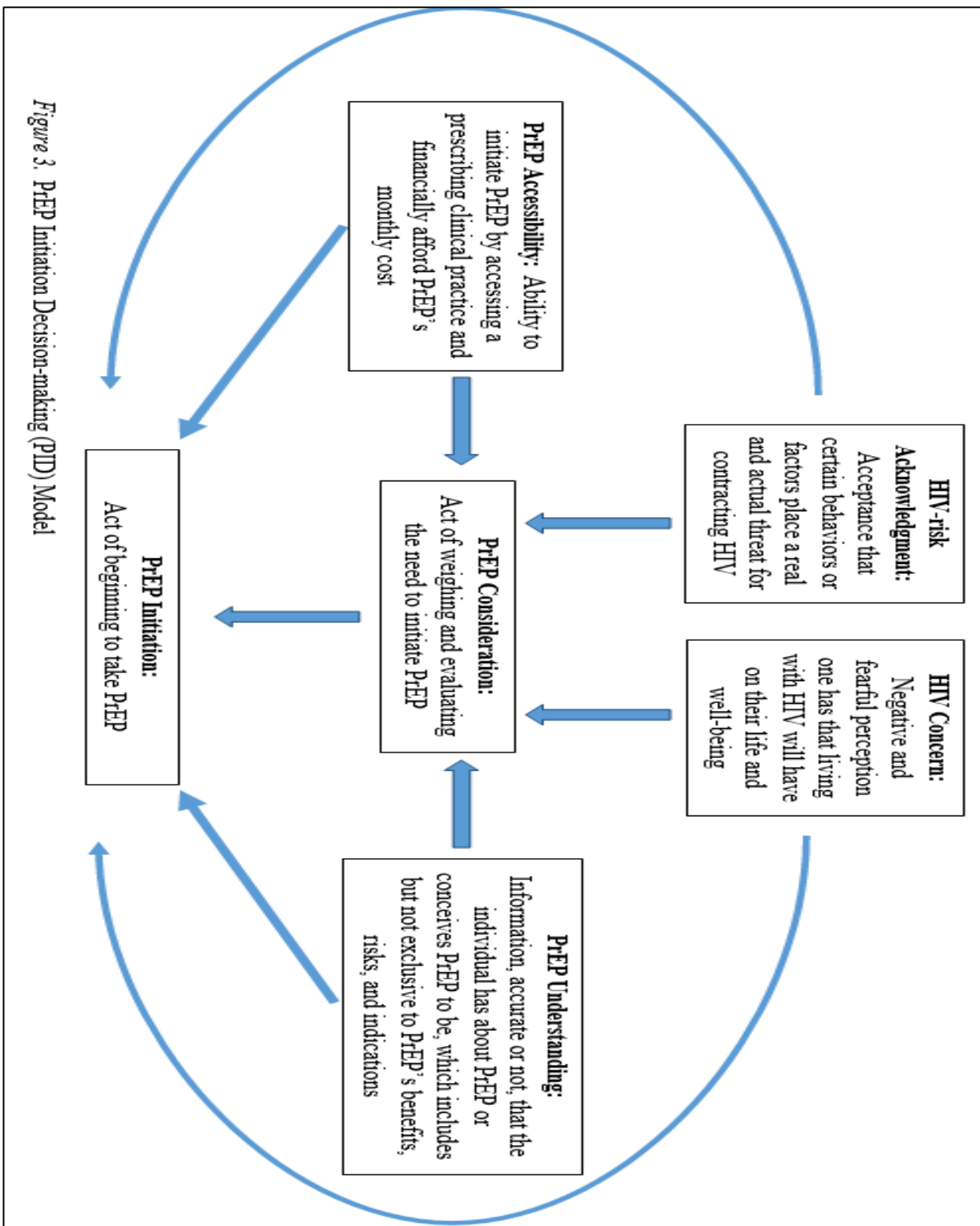


Figure 3. PrEP Initiation Decision-making (PID) Model

### Summary

Fourteen MSM residing in the Southern U.S. participated in the study. The mean age for this predominantly African-American (10/14, 71%) sample was 34 years. Additionally, most participants (6/14, 43%) identified as having a low socioeconomic status (SES) of an annual income of less than \$20,000. Although this sample was not significantly diverse, the findings were insightful, providing rich data on PrEP initiation decision-making process in a sub-sample of MSM.

The data indicated this sample's decision to initiate PrEP to be a phenomenon of considering specific aspects surrounding HIV and PrEP. The emerging themes were identified as HIV-risk behaviors and factors, deception, and HIV/STI scares. The data also revealed this sample viewed living with HIV to be burdensome and life altering, inflicting both social and physical hardships. In regards to PrEP, the related themes in the decision-making process pertained to knowledge and understanding of PrEP's indications, benefits, risks, costs, as well as the ability to afford and access PrEP services. The data demonstrated that these themes were considered individually and collectively, leading to their decision to initiate PrEP. These themes were organized into five broader categories: HIV-risk acknowledgement, HIV concern, PrEP understanding, PrEP accessibility, and PrEP consideration.

From the data, the PID model emerged as a conceptualization depicting this sample's decision-making process. The PID model explains these participants initiated PrEP after considering their perceptions, attitudes, and personal characteristics surrounding their (1) acknowledged HIV-risks, (2) HIV concerns, (3) PrEP understanding, (4) PrEP accessibility, and (5) PrEP consideration. Additionally, the data showed this sample's PrEP initiation decision-

making to be a non-linear process, as there was no specific or patterned sequence in which each concepts was weighed or considered.

## Chapter 5: Conclusions and Recommendations

HIV pre-exposure prophylaxis (PrEP) is the inaugural pharmacological HIV-preventative agent approved in the U.S. (CDC, 2014b). PrEP is the fixed daily dose of Truvada, an antiretroviral (ART) shown to reduce HIV risk by as much as 92%, and is therefore indicated in HIV-negative persons with reported and documented high HIV-acquisition risk (CDC, 2014b). Although other at-risk groups exist, men who have sex with men (MSM) experience the most disparaging HIV rates in the U.S., accounting for 55% of people living with HIV (PLWH) and majority of new HIV infections nationally and among men each year (CDC, 2016c). MSM's engagement in anal intercourse (AI) with other men is the primary catalyst driving their HIV incidence disparity. AI in MSM is the overall most common mode of HIV transmission (CDC, 2016d), and the riskiest type of sex (CFA, 2014; Pebody, 2010). Most current and former PrEP patients are MSM (Krakower et al., 2015; Krakower & Mayer, 2015; Tellalian et al., 2013); however currently there is a paucity of literature on PrEP initiation decision-making in any population.

Guided by the Information-Motivation-Behavioral (IMB) skills model, the following research question was proposed: How do HIV-negative MSM engaging in protected or unprotected AI decide to initiate PrEP? The study objective was to explore how HIV-negative MSM decide to initiate PrEP based on the evaluation and perceptions pertaining to their: (a) PrEP knowledge and HIV concern(s)/risk(s); (b) personal and social motivations to initiate PrEP; and (c) behavioral skills and abilities to adhere to PrEP. A qualitative study was conducted with a six-item theory derived questionnaire, and analysis of the one-on-one semi-structured interviews of 14 MSM living in the Southern U.S. revealed several HIV and PrEP themes to be a part of this investigated phenomenon. To answer the research question, this sample of MSM

decided to initiate PrEP by considering the perceived benefits and risks of initiating PrEP based on their (1) acknowledged HIV-risks, (2) HIV concerns, (3) PrEP understanding, (4) and accessibility to PrEP.

This chapter details the conclusions and recommendations drawn from the study's findings. The investigator will expound on the answer to the proposed research question. From the answered research question, the investigator will discuss the implications the findings have on the reviewed literature, as well as the health-care industry and nursing profession. Based on the pre-identified study limitations, the investigator will make recommendations for future research. Lastly, the investigator will make three critical conclusions drawn from these findings.

### **Discussion**

This sample of HIV-negative MSM decided to initiate PrEP after assessing and evaluating their perceptions regarding their (1) acknowledged HIV-risks, (2) HIV concerns, (3) PrEP understanding, (4) PrEP accessibility, and (5) PrEP consideration. From the data, the investigator was able to define and establish relationships between each of these concepts. From the inductive content analysis process, these five broader categories emerged as constructs in the PrEP initiation decision-making (PID) model, a conceptualization of this sample's defined non-linear and introspective process of deciding to initiate PrEP.

HIV risk and concern were significant factors in the PrEP initiation decision-making process. HIV-risk acknowledgment was found to be the moment or event that makes the threat of contracting HIV real and apparent. This acknowledgement comes in the person's own time and is based on their own perception and understanding of HIV. Additionally, the acknowledgment is the result of a self-assessment of how much the individual believes they are at risk for contracting HIV, and can be triggered by a recent, planned, or a lifetime of

experiences and events. HIV concern was shown as the negative and fearful perception that living with HIV will have on one's life and well-being. Like HIV-risks, participants' HIV concern was discovered to evolve from their experiences and perceptions on the hardships encountered by PLWH and their understanding of HIV's disease progression and manifestation. While these two individual concepts do not impact or influence the other, they both impact the decision to initiate PrEP, as a greater belief in one's acknowledged HIV-risks and more HIV concern was revealed to directly influence this sample's decision to initiate PrEP.

Aspects of PrEP were also a part of the process including understanding and accessibility. PrEP understanding was the information, accurate or not, that the individual has about PrEP or conceives PrEP to be, which includes but is not exclusive to PrEP's benefits, risks, requirements, and indications. Participants sought additional information from various sources, and despite reported misconceptions or uncertainties, participants decided to initiate PrEP. Participants believed that their HIV risks and concerns outweighed any lingering or existing concerns or uncertainties about what they knew or perceived about PrEP. Despite the possibilities of participants receiving or perceiving erroneous and misconceived PrEP information, participants processed and utilized that information the same. As more knowledge was gained, participants believed they had a better understanding about PrEP's benefits, risks, and indications. Each individual felt comfortable with their understanding of the information they obtained, but being comfortable did not alleviate all lingering thoughts, concerns, uncertainties, or inconveniences. Instead, they decided to initiate PrEP based on the PrEP knowledge and understanding they had at the time of initiation, because PrEP's added HIV protection out-weighed those wavering thoughts, concerns, uncertainties, or inconveniences. PrEP accessibility was the ability to access PrEP both financially and from a prescribing clinical practice. PrEP cannot be initiated without

the services of health professionals, so while the investigator knows access to a provider was key to the decision-making process, the data could not determine the impact or influence PrEP services being conveniently or inconveniently located had on the decision-making process. Lastly, PrEP consideration was shown to be the act of weighing and evaluating the need to initiate PrEP based on the other four factors. Like the four concepts, the result of their PrEP consideration was shown to influence their decision to initiate PrEP. The extent and consideration each aspect was viewed or valued was person specific, as one person's value system was demonstrated to be unique and specific to them.

Conceptualization of this sample of MSM's PrEP initiation decision-making process makes a significant contribution to the literature. In order to understand this impact, the investigator will compare this data derived model to another model commonly used in HIV health behavioral decision-making research. The investigator will identify consistencies and inconsistencies these findings have to the reviewed literature. Given the initial knowledge gap and study limitations, the investigator will reveal and discuss the contribution these findings make to the current knowledge gap on PrEP initiation in the U.S.

### **Model Comparison**

The IMB skills model guided this inquiry and the resulting conceptualization of this sample's PrEP initiation decision-making process is reflective of the IMB skills model. The IMB skills model conceptualizes the decision to initiate HIV risk-reduction behaviors as involving one's information, motivation, and skills regarding the HIV preventative behavior (Aliabadi et al., 2015; Amico et al., 2005; Amico et al., 2009; Chang et al., 2014; Fisher & Fisher, 1992; Macapagal et al., 2016; L. Smith et al., 2012). Information is the knowledge, myths, and understanding the individual has about the preventative measure, while skills are the

abilities needed to perform that behavior (Aliabadi et al., 2015; Amico et al., 2005; Amico et al., 2009; Chang et al., 2014; Fisher & Fisher, 1992; Macapagal et al., 2016). Motivation, however, encompasses two forms, personal and social. Personal motivations are the attitudes, beliefs, and perceptions regarding the outcomes from performing or not performing that behavior, and social motivations are the perceived social support and acceptance from peers or partners from performing the behavior (Aliabadi et al., 2015; Amico et al., 2005; Amico et al., 2009; Chang et al., 2014; Fisher & Fisher, 1992; Macapagal et al., 2016).

When comparing the IMB skills model to the PID model, the PID model demonstrates that the decision to initiate PrEP is dependent upon an individual's acknowledgment of their HIV risks and out of concern from implications of living with HIV, which is congruent with the IMB skill model's HIV information concept. Additionally, the PID model shows that their decision to initiate PrEP was also derived by their PrEP understanding, which is the accepted perception of PrEP to provide added protection, and the ability to access PrEP financially and logistically, which mirrors the IBM skill model's concepts of personal motivation and behavioral skills, respectively. The distinction between these two models is the inclusion of social motivation and the absence of PrEP consideration in the IMB skills model. Although apparent in the IMB skills model, the PID model does not conceptualize the influence and reactions from an individual's peer group to be a part of the decision-making process. Likewise, the PID model recognizes individuals take a moment to evaluate and weigh all the information they have attained (i.e., acknowledged HIV risks, HIV concern, PrEP understanding, and PrEP consideration) in order to derive that the benefit of initiating PrEP was worth given their perception of the model's four other and influential entities.



The PID model emulates the Health Belief Model (HBM), a health behavioral theoretical framework historically used to investigate HIV risk-reduction decision-making. The HBM was developed in the 1950s and 1960s by social psychologists Hochbaum, Rosenstock, and Kegels, as a cognitive representation of one's likelihood or intention of performing health behaviors (Jones et al., 2014; Li et al., 2016; Montanaro & Byran, 2014; Schnall et al., 2015). The HBM's outcome of intention and not implementation was the rationale this investigator did not apply the HBM to guide this inquiry, but the HBM has merit in HIV related investigations. Data analysis from this study revealed the PID model to represent this sample's decision-making process for actually implementing the investigated behavior. While the HBM and the PID model differ in outcomes, they are comparable, encompassing similar concepts and assumptions.

The HBM depicts one's perceptions, attitudes, and personal characteristics to explain or influence health behavioral decisions (Schnall et al., 2015), and shares similarities with this study's data derived model. The PID model emulates the HBM, as five concepts: (1) acknowledged HIV-risks, (2) HIV concerns, (3) PrEP understanding, (4) PrEP accessibility, and (5) PrEP consideration were revealed to influence this sample's PrEP initiation decision-making process. Under the HBM one's perceptions and attitudes towards the disease and behavior, along with one's personal characteristics (i.e., personal demographics factors, socioeconomics and knowledge), are equivalent to the concepts of acknowledged HIV-risks, PrEP understanding, and PrEP accessibility. One's perception regarding HIV susceptibility/threat, severity of disease, and the behavioral changes' benefits and barriers are apparent in this model as acknowledged HIV-risks, HIV concerns, and PrEP understanding. Additionally, the HBM's financial and personal characteristics to the particular behavior mirrors this study's accessibility to PrEP services. Given the HBM's credibility in the field of health-behavioral and HIV research, the

fact that the PID model shares some similarities with the HBM, brings credibility to this data derived conceptualization.

### **Model Assumptions**

Like the HBM, the PID model is privy to assumptions. In order to make a decision about a choice or decision, one has to be knowledgeable of the choice or option. The HBM also assumes individuals are rational, as their behaviors reflect their thought processes, and behavioral change decisions arise from a concern or threat of disease (Champion & Skinner, 2008). Likewise, this study and therefore the results from this study presume that participants instituted prevention behaviors due to HIV concerns and desire to prevent contracting the disease. Therefore, both the HBM and PID models assume that the process cannot occur until the need for behavioral change or awareness occurs. The data demonstrated that the fear or concern the individual has regarding HIV is not only an assumption, but also a factor and concept incorporated in the model. Additionally, the PID model assumes that the decision-making process occurs regardless of one's known or assumed HIV status. The reason HIV status is not a factor in initiating the process is due to the second assumption. While PrEP is indicated for HIV negative persons, the data showed that PrEP misconceptions existed upon patients becoming aware of PrEP's clinical indications. Thirdly, this model also assumes the process does not have a defined beginning point, as the data did not indicate a sequence in which of the four primary concepts were considered first. Participants were shown to go through and consider each of these concepts one at a time and/or simultaneously.

These findings share consistent and inconsistent aspects with the reviewed literature pertaining to health-behavioral decision-making, MSM HIV prevention, and MSM and PrEP.

Comparing the reviewed literature to this study's evidence identifies the contribution the findings make to the literature and current knowledge gap.

### **Health Behavioral Decision-making**

Consistent with this investigation's literature review and theoretical framework, this study found that the sample's PrEP initiation decision-making process was an individualistic process of weighing and considering different factors. Systematic and meta-analysis research repeatedly identified those factors to involve one's personal and social circumstances (Poortaghi et al., 2015; Popejoy, 2005). Additionally, knowledge and perspectives about health, the health behavior, and the disease or condition itself are also weighed in this process (Bui et al., 2014; Clifford et al., 2017; Dugas et al., 2017; Hamilton et al., 2016; Keatley et al., 2013; Newson et al., 2013; Nichol et al., 2011). In this study, participants readily identified the behaviors placing them at risk for contracting HIV, and from that acknowledgment, they perceived a genuine and real HIV threat to exist. This study found participants to have an overwhelming fear of HIV from a lifetime of interacting with or hearing about social and health hardships associated with being HIV-positive. Not wanting to endure such hardships motivated participants to initiate PrEP. Participants made decisions based on their own evaluation of PrEP's benefits, risks, and requirements. Lastly, participants' financial means greatly determined their decision to initiate PrEP, as all needed some form of assistance to access PrEP. Consistent with the literature, this process was introspective, determined by the individual and based on their experiences regarding HIV and PrEP knowledge.

Also consistent with the literature, the findings acknowledged the role of health professionals in health related decision-making. The literature showed that health professionals play an important role in patients' decision-making process (Chong et al., 2013; Coombs et al.,

2016; Popejoy, 2005; Rose et al., 2017; Siouta et al., 2015; Thom et al., 2016). For example, health professionals coach and support patients when deciphering between health choices (Popejoy, 2005; Thom et al., 2016). Health professionals educate and clarify misunderstandings regarding health-care options, and they assist patients in making an appropriate decision based on the patient's self-defined goals (Popejoy, 2005; Thom et al., 2016). Additionally, the CDC's compendium synthesis demonstrated that health professionals are integral to increasing MSM's use of risk-reduction behaviors, as MSM need support and guidance from a professional, trusted resource, or program knowledgeable in HIV prevention in order to increase utilization of HIV risk-reduction behaviors (CDC, 2017a, 2017c). The literature showed that patients are receptive to information utilizing open communication, transparency, and a non-judgmental exchange of information (Carvajal et al., 2017; Chong et al., 2013; Siouta et al., 2015; Thom et al., 2016). Although PrEP is only accessible from a prescribing practice, some participants did not perceive that they received such in-depth education, as they admitted to initiating PrEP with lingering doubt, uncertainties, and misconceptions. On the other hand, some participants expressed that the counseling and education they received from health professionals was integral to them having a clear understanding, leading to their decision to initiate PrEP. Additionally, participants who received in-depth patient education from health professionals prior to initiating PrEP appeared to be more assured and confident in their choice. Therefore, consistent with the literature, this study's evidence demonstrated that providing patients with complete and transparent PrEP education is conducive to their decision-making process.

Inconsistent with the literature was the influence external and other social pressures had on this sample's decision-making process. The IMB skills model conceptualizes the decision to initiate HIV risk-reduction behaviors to include social motivations like perceived support and

acceptance from peers and significant others (Aliabadi et al., 2015; Amico et al., 2005; Amico et al., 2009; Chang et al., 2014; Fisher & Fisher, 1992; Macapagal et al., 2016). This study's data did not demonstrate such influence from peers, family members, or partners to be included in the process, as the data revealed the process to be introspective. However, participants were aware and reported the negative and social stigmas associated with PrEP. While social motivations were not seen to be directly a part of this sample's PrEP initiation decision-making process, the investigator recognizes that it is possible that social motivations could have had an indirect or subconscious effect on this sample's decision-making process. Additionally, the investigator acknowledges that lack of social motivation in this process may not be true with other patients who have initiated or are deciding to initiate PrEP.

### **MSM HIV Prevention**

This study's findings share consistencies with the literature regarding HIV concern from susceptibility and living with the virus being a factor in MSM's implementation of HIV prevention behaviors. Systematic reviews demonstrated that HIV-negative MSM are concerned about contracting HIV (Balan et al., 2013; Neville & Adams, 2009; Neville et al., 2016). Likewise, study participants shared and expressed significant concerns and fears regarding HIV, as HIV was perceived as a life altering and devastating disease. Participants repeatedly cited stories of PLWH to experience depression, rejection, and other social hardships, and these hardships were perceived to be attributed from PLWH's HIV-positive status. In other publications, MSM were shown to no longer view HIV as a serious problem or public health issue due to ART transitioning HIV into a chronic disease (Balan et al., 2013; CDC, 2016b; Neville et al., 2016; Neville & Adams, 2009). The literature demonstrated conflict regarding the impact HIV concern has on MSM's HIV prevention decision-making, and it was apparent in this

study. This sample exhibited conflict, as they acknowledged PLWH can live a normal life if on effective HIV treatment, but they were extremely fearful of HIV's social and physical implications.

Trust was found to be a part of this sample's decision-making process, but is inconsistent with the current literature. The reviewed literature showed partner conversations and emotions to influence MSM's decision-making to utilize HIV prevention behaviors. Partner conversations encompass a couple's discussion of the relationship status and HIV status and risks, and that information is used to determine their utilization of risk-reduction behaviors (Campbell et al., 2014). In addition, the literature found MSM to rely on emotions erroneously to derive the need to use risk-reduction behaviors (Bauermeister et al., 2009; Campbell et al., 2014; Goldenberg et al., 2015; Green et al., 2014). Both partner conversations and emotions require a level of trust, as partners do not perceive their counterparts to be deceptive; however, this sample of MSM perceived there to be a significant amount of deliberate HIV deception and lack of disclosure. This sample found it difficult to trust people regarding their HIV statuses even within the context of an established or committed relationship. This perception of deception heightened this sample's HIV risks, influencing their decision to initiate PrEP as a way to take control of their HIV risk.

### **MSM and PrEP**

Although currently PrEP initiation decision-making research is absent from the literature, this study's findings are consistent with evidence regarding MSM's interest and intention to initiate PrEP. Previous studies found that MSM to be interested in PrEP to promote health and enhance sexual pleasure (Brooks et al., 2012; Collins et al., 2016; Gamarel & Golub, 2015; Garcia & Harris, 2017; Golub et al., 2013; Mimiaga et al., 2014; Oldenburg et al., 2016; Taylor

et al., 2014), as PrEP is perceived as a proactive form of HIV prevention as opposed to reactive (Oldenburg et al., 2016). During PrEP clinical trials, the literature showed MSM subjects to initiate PrEP out of motivation to protect themselves from future HIV infections (Taylor et al., 2014). Previous investigations found patients initiated PrEP for additional HIV protection given their HIV risks including multiple sex partners, condom failures, and inconsistent or no condom use (Collins et al., 2016; Garcia & Harris, 2017; Parker et al., 2015). The added protection reduces anxiety and shame associated with risky sexual behaviors (Brooks et al., 2012; Collins et al., 2016; Taylor et al., 2014), and fears of contracting the virus when engaging in AI with a person who has a positive or unknown HIV status (Mimiaga et al., 2014; Oldenburg et al., 2016; Taylor et al., 2014). This study's evidence is consistent with the literature, as this sample initiated PrEP for added HIV protection due to the behaviors placing them at HIV risk (i.e., multiple sex partners, inconsistent condom use, condom failures, HIV deception, lack of HIV disclosure, AI, MSM HIV disparity, STI/HIV scares etc.). PrEP's added HIV protection, provided peace of mind, which decreased anxiety and fear during sexual encounters; however, this added peace of mind has caused have a dreaded consequence for some participants.

This evidence showed that risk compensation was a consequence of PrEP initiation providing the added peace of mind and HIV-protection, which is consistent with the literature. Risk compensation is the purposeful increase in HIV risky behaviors (Blackstock et al., 2016; Calabrese et al., 2014; Calabrese & Underhill, 2015; Karris et al., 2014; Yagoda & Moore, 2016). The literature showed MSM assume their peers would initiate PrEP purposefully to engage in risky behaviors (Brooks et al., 2012; Collins et al., 2016; Garcia & Harris, 2017; Golub et al., 2013; Oldenburg et al., 2016; Perez-Figuerora et al., 2015; D. Smith et al., 2012; Taylor et al., 2014). Three of the fourteen participants reported a form of risk compensation, as

they reported engaging in riskier sex since their initiating PrEP. Although only one participant admitted that engaging in risk compensation was the reason he initiated PrEP, the fact that two other participants reported behaviors indicating risk compensation does give speculations about risk compensation influencing PrEP initiation to have some validity.

Consistent with the literature, these findings show social barriers to accessing PrEP. Perceived negative stigma and judgmental reactions from peers and health professionals were speculated to deter MSM from seeking and initiating PrEP (Auerbach et al., 2015; Collins et al., 2016; Dolezal et al., 2015; D. Smith, et al., 2012). The data are consistent with the literature, as participants reported the negative or erroneous social perception about PrEP. Although this sample did not report the social stigma to influence their decision, the investigator acknowledges that those social motivations could have subconsciously influenced their decision, and may possibly influence other at-risk individual's decision-making process. Cost has also been shown to be a barrier to initiation, as studies showed patients would be more willing to use PrEP if it was conveniently available at minimal or no cost (Golub et al., 2013; D. Smith et al., 2012). This study's data did find financial means to be a factor in PrEP initiation, as participants openly voiced that they were unable to access PrEP without assistance, and this perspective was apparent regardless of SES. Due to most participants accessing PrEP at minimal or no cost, the investigator cannot determine PrEP's value limit to this sample. Another aspect of accessing PrEP is provider and clinical services availability. Approximately 9% to 34% of prescribing providers have adopted PrEP guidelines into their practices (Blackstock et al., 2016; Hakre et al., 2016), and 30% of providers who have never prescribed PrEP believe they are unlikely do so (Krakower et al., 2015). Although most of this sample did not have challenges in locating a PrEP provider, one participant did experience such challenges. Therefore, this data



demonstrated that access due to financial or provider means is ongoing, and implicates other at-risk individuals or populations wanting to initiate PrEP, but have accessibility constraints.

### **Knowledge Gap Contribution**

Prior to this investigation, an absence of PrEP initiation decision-making inquiries in any population existed. Therefore, this evidence is foundational to the current knowledge gap regarding PrEP decision-making. The proposed investigation contributes to filling this knowledge gap, as the purpose was to explore MSM's decision to initiate PrEP, and the findings revealed the factors and process involved in how this MSM sample derived to their decision. Additionally, the evidence confirmed that initial misconceptions about PrEP's indications and requirements exist. This study demonstrated that patients require support, education, and counseling when considering PrEP initiation from knowledgeable health professionals. Although these findings are specific for this sample of MSM, the findings provide insight into the factors and process of PrEP initiation decision-making, which may occur in other patient populations.

Despite this contribution, study limitations restrict the magnitude these findings have on the literature. The investigator utilized a qualitative description approach, as it is synonymous with naturalistic research, and appropriate for decision-making research. Decision-making is the process in which individuals consider and evaluate different factors surrounding a choice or option, making it an individualistic and value dependent phenomenon (Allan & Harden, 2014; Bui et al., 2014; Clifford et al., 2017; Dugas et al., 2017; Hamilton et al., 2016; Keatley et al., 2013; Newson et al., 2013; Nichol et al., 2011; Popejoy, 2005; Schmidt et al., 2016; Tranberg et al., 2016). Therefore, this study's findings are limited by respondent and interviewer bias, as participant dishonesty or investigator misinterpretation could have distorted the emic view,

leading to an inaccurate representation of this sample's PrEP initiation decision-making process. To the investigator's knowledge, this was the first investigation into PrEP initiation decision-making in any population, therefore, the trustworthiness of these findings are restricted. The investigator recognizes that other HIV-negative MSM may or may not undergo the same process when making their decision. Additionally, even if the process is the same, the extent and degree in which these factors are perceived and evaluated could also vary. Given the personal nature of decision-making, qualitative methodology, and this study being the first known inquiry into MSM's PrEP initiation decision-making process, these findings are limited by transferability, preventing these findings from being applicable to the larger MSM population. In light of the identified limitations, the investigator cautions against health professionals generalizing these findings to all applicable MSM patients, as these findings are transferable to this sample, and possibly to other MSM sharing similar social demographics, experiences, and PrEP accessibilities.

### **Implications**

Despite these limitations, the findings provide insight into this phenomenon, and are significant to the future narrative surrounding PrEP and HIV. Specifically, these findings have cost saving implications for the health-care system regarding the U.S. HIV epidemic, and the role nursing practice, education, and research has in providing PrEP care and services.

### **Health-care Industry**

These findings are foundational to gauge if and how PrEP will have an impact on the current MSM HIV epidemic. HIV care and treatment is extremely expensive on the health-care system, costing an estimated \$12.3 billion annually (CDC, 2015a). PrEP initiation in at-risk groups is estimated to reduce HIV incidence by 70%, preventing 185,000 U.S. infections by

2020 (CDC, 2016e), and each prevented HIV infection saves an estimated \$355,000 in lifetime HIV treatment costs (CDC, 2015a). In order for this to be possible, individuals with PrEP indications have to decide to initiate the complementary regimen.

For this sample, each participant reported having at least one high HIV risk factor, therefore showing that this sample of MSM were appropriate PrEP candidates. While analysis of several themes lead to the discovery of five themes to entail their decision-making process, the data indicated that acknowledged risks and HIV concern to be heavily weighted in the process. This data demonstrated this predominantly African-American sample to be cognizant of the epidemic, and were thorough when identifying factors placing them at risk. These findings implicate other individuals with significant HIV risk factors who are knowledgeable of PrEP, but have not decided to initiate PrEP. Perhaps this data provides a plausible explanation for PrEP's slow initiation in the U.S., as other at-risk individuals have not acknowledged their HIV risks, or perceived HIV epidemic to be a threat or to even exist. Another possibility is that these other at-risk persons are deterred from initiating PrEP due to the on-going negative and social stigma associated with PrEP.

One population in particular these findings have implications for is African American women, as the CDC (2016d) indicates African American women to be the second highest group infected with HIV after MSM. Additionally, data shows that African-American women are more than four times less likely to initiate PrEP than Caucasian women, as most PrEP patients are male (76%) and only 10% of African-Americans have initiated PrEP (NAM, 2018). This study's evidence implicates that without other at-risk populations acknowledging the epidemic or their risks, PrEP initiation may remain slow, and PrEP's estimated impact will not be realized.

Given some of the barriers (i.e., stigma, cost, and logistics) identified from and experienced by this sample, this investigator believes the evidence implicates a need for discussing the need to devise policies that can address individuals with PrEP indications being able and willing to access and initiate PrEP. This evidence implicates the need to consider the development of policies to improve and expand PrEP outreach and access to services to HIV-vulnerable groups throughout the U.S. This sample expressed disappointment in their own experiences and perception of society's knowledge and awareness of PrEP. While some participants acknowledged PrEP awareness is low and poor among all patient populations, most recognized that HIV-vulnerable populations such as MSM, youth, women, and minorities suffer greatly from the lack of awareness, as the CDC (2016f) identifies these groups as the most vulnerable to contracting HIV. Increased and widespread PrEP education and outreach from knowledgeable professionals and advocates can be a mechanism to increase awareness and decrease PrEP's negative stigmas and erroneous misconceptions.

This sample also expressed difficulty in accessing PrEP without financial assistance, implicating the need for federal and state aid to fund PrEP preventative services just as HIV/AIDS' treatment efforts are rendered through state level AIDS Drug Assistance Programs (ADAP), and federal Ryan White services. Although only one participant experienced logistical issues to accessing a PrEP provider in their local area, this one occurrence does give speculation that such challenges are apparent for other at-risks persons in areas lacking PrEP services. Previous evidence demonstrated that the limited number of PrEP providers is not merely an act of a knowledge deficient. Less than 20% of sampled providers in the U.S. have ever prescribed PrEP (Krakower et al., 2015; Tellalian et al., 2013), and 30% of providers who have never prescribed PrEP believe they are unlikely do so in the future (Krakower et al., 2015). These

limitations give reason for the need for devising strategies to overcome such challenges.

HIV/AIDS' advocates should consider lobbying for the opportunity to discuss instituting funding and policies to support providing PrEP-care through telemedicine capabilities, or by requiring health professionals to inform patients about PrEP and the clinics in their local and neighboring areas that can provide such services.

### **Nursing Profession**

These findings allow nursing to improve practice and education PrEP standards. Most participants engaged in risky sexual behaviors prior to PrEP initiation (i.e., multiple sex partners, using condoms inconsistently or not at all, and engaging in open/casual/impulsive sex), and this evidence reminds nurses to provide risk reduction counseling regardless of the patient's decision to initiate PrEP. The evidence showed the rationale behind this sample's decision to initiate PrEP. The identified themes (i.e., HIV risks, fears, concerns; and PrEP risks, benefits, and requirements) can be used as a guide to provide in-depth PrEP patient education during the screening and initiation process. The data showed that participants initiated PrEP without having a complete understanding of or accurate information about PrEP's requirements and efficacy. Nursing practice can utilize this evidence to implement in-depth PrEP patient-education, ensuring that patients are explicitly educated about the correlation between adherence and efficacy, as well as PrEP's effectiveness timeframes. Initiating PrEP was revered as a form of proactive prevention which gave participants more control of their HIV risks and peace of mind; however, as a result, risk compensation was noted from a few participants, implicating the need for nursing practice to educate patients that PrEP is complementary, requiring the implementation of traditional risk-reduction behaviors in combination with PrEP. Another aspect identified in the decision-making process is the impact affordability had on initiation, as

all participants admitted to being PrEP's cash price to be exorbitant. From this evidence, nursing practice can better advocate for patients, ensuring that all are aware of PrEP access and financial assistance programs.

This study's evidence is foundational for nursing research, establishing a new knowledge base for PrEP initiation inquiries to build upon. Future inquiries can replicate this study design utilizing a larger sample size, to further evaluate and explore these findings. Replicated studies can refine the data derived conceptual model, and are necessary before transferring the findings to the larger population (Houghton et al., 2013). Although this data is specific to MSM in the Southern U.S., this evidence can be foundational to investigating PrEP initiation decision-making in other patient populations and U.S. regions. As more evidence is generated, sequential findings can lead to the development of evidenced-based PrEP initiation decision-making practice interventions and tools, which can lead to devising and implementing evidenced based strategies for achieving PrEP initiation success.

### **Recommendations for Future Research**

This evidence adds to the PrEP initiation literature, but as foundational evidence, there are opportunities for future research. Given the limitations and implications associated with this inquiry into a new phenomenon, the investigator recommends replication of this study utilizing more MSM PrEP patients in the Southern U.S. PrEP initiation decision-making should also be studied in different patient demographics to determine differences and similarities among the populations. Although foundational for PrEP initiation, this data does not address other aspects of post-PrEP initiation, including adherence, risk compensation, decision-making to continue or discontinue PrEP, and long-term efficacy. Therefore, inquiries into these aspects surrounding PrEP initiation are recommended in all populations initiating PrEP. Investigation into these

other PrEP aspects provides a comprehensive account of PrEP implementation in the U.S., and PrEP's ability to have the estimated impact on the HIV epidemic in the U.S.

### **Conclusions**

This investigation into MSM's PrEP initiation decision-making process was shown to be a personal and introspective phenomenon. This evidence shares consistencies with the reviewed literature and extends the knowledge base on health-behavioral decision-making, MSM HIV prevention, and MSM and PrEP. Although these findings are limited and not readily applicable to all MSM or other patient populations, these findings are significant to PrEP initiation in the U.S., as three significant conclusions are drawn from this data. The investigator concludes that the decision to initiate PrEP is a serious endeavor. Secondly, PrEP is still a negatively stigmatized regimen, which has implications for PrEP initiation in the future. Therefore, health professionals involved in any aspect of rendering PrEP services should be adequately educated to combat misconceptions and misunderstandings.

The data showed that in spite of PrEP's benefits to provide added HIV protection, participants engaged in serious thought process prior to initiating PrEP. Participants did not take this decision lightly, as analysis of the data emerged a comprehensive process in arriving at the decision. Each participant did not report being overzealous or eager to initiate PrEP just to reap the benefits of having added HIV protection, instead the process was comprehensive and an evaluation encompassing these five concepts (1) HIV-risk acknowledgment, (2) HIV concern, (3) PrEP understanding, (4) PrEP accessibility, and (5) PrEP consideration. Although more evidence is needed on risk compensation in the context of PrEP initiation, this evidence showed that participants are not initiating PrEP with the intent to engage in riskier HIV and sexual behaviors.

Although this sample did not show social motivations and social stigmas to influence their decision-making process, the data indicated that a significant amount of erroneous and negative information exist about PrEP. As the literature suggested, these social motivations can influence decision-making process whereby deterring other at-risk populations from initiation (Auerbach et al., 2015; Collins et al., 2016; Dolezal et al., 2015; D. Smith, et al., 2012). Therefore, health professionals have to be knowledgeable of these social perceptions and opinions, so that they can be prepared to address these misconceptions with the patients and communities being served, especially those experiencing the highest HIV incidence and prevalence.

Lastly, this evidence leads to the conclusion that all health professionals providing any aspect of PrEP services should be knowledgeable to provide accurate PrEP patient-education. Health professionals play a significant role in patients' decision-making processes (Chong et al., 2013; Coombs et al., 2016; Popejoy, 2005; Rose et al., 2017; Siouta et al., 2015; Thom et al., 2016). Since PrEP is only accessible from the services of health professionals, ideally, there should not be a reason a patient whom has initiated PrEP should have lingering uncertainties or misunderstandings about PrEP. Health professionals that are involved in any aspect of PrEP care, beginning with screening, to initiation, to dispensing, to follow-up care, and discontinuation are charged to provide education at any interim during this care continuum. Given PrEP's uniqueness to traditional risk-reduction behaviors, this study's evidence requires health professionals to be vigilant and proactive in the PrEP care and patient education provided.



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## Appendix A: CDC's MSM HIV Prevention Evidenced-based Behavioral Interventions (EBIs)

<b>Name</b>	<b>Level</b>	<b>Facilitator &amp; Description</b>	<b>Effectiveness</b>
Males of African American Legacy Empowering Self (MAALES)	Group	Facilitator: African-American males  Description: Delivery of six-2 hour sessions over a 3 weeks and two-2-hour booster sessions at 16 & 18 weeks post-intervention.	Good
Many Men, Many Voices (3MV)	Group	Facilitator: Peer-to-Peer  Description: Six consecutive 2 to 3-hour sessions during a weekend	Best
Mpowerment	Community	Facilitator: Outreach Team of MSM peers  Description: A team of 10-15 young gay men design and carry out our integrated activities: (1) formal outreach, (2) informal outreach; (3) "M-group"; & (4) ongoing publicity campaigns that provide skill building, practice correct condom-use, & safer-sex negotiations	Good
No Excuses/ Sin buscarexcusas	Group	Facilitator: Technology (video) & Peer counselor  Description: One 45-minute soap-opera style video in English & Spanish followed by discussions	Best
Personalized Cognitive Counseling (PCC)	Individual	Facilitator: Licensed mental health professional  Description: One 1-hour counseling session	Best
Popular Opinion Leader (POL)	Community	Facilitator: Trusted & respected community leaders  Description: MSM community leaders are trained to engage in risk-reduction conversations with peers.	Good
POWER	Individual	Facilitator: Virtual facilitator  Description: Three 60-90 minute counseling sessions delivered over 3 weeks followed by discussions	Best
Project ECHO	Individual	Facilitator: Professional Counselor  Description: One 30-50 minute Personalized Cognitive Counseling (PCC); One booster counseling session three months later	Best
Think Twice	Individual	Facilitator: Peer-to-Peer  Description: One 40-minute session	Best
VOICES/VOCES	Individual	Facilitator: Technology (video) & male facilitator  Description: One 20-minute video (culturally adapted for African Americans & Hispanics) followed by one 25-minute group discussion	Best
Young Men's Health Project	Individual	Facilitator: Professional Therapist  Description: Four 1-hour sessions delivered over 12 weeks	Best

## Appendix B: Applied Theoretical Frameworks in CDC's Compendium Interventional Studies

<b>Intervention Name</b>	<b>Theoretical Framework(s)</b>
Males of African-American Legacy Empowering Self (MAALES)	<ul style="list-style-type: none"> <li>• Theory of Reasoned Action/Theory of Planned Behavior</li> <li>• Empowerment Theory</li> <li>• Critical Thinking and Cultural Affirmation Model</li> </ul>
Many Men, Many Voices (3MV)	<ul style="list-style-type: none"> <li>• Social Cognitive Theory</li> <li>• Behavioral Skills Acquisition Model</li> <li>• Transtheoretical Model of Behavior Change</li> <li>• Decisional Balance Model</li> </ul>
Mpowerment	<ul style="list-style-type: none"> <li>• Diffusion of Innovations Theory</li> </ul>
No Excuses/ Sin buscarexcusas	<ul style="list-style-type: none"> <li>• Social Cognitive Theory</li> </ul>
Personalized Cognitive Counseling (PCC)	<ul style="list-style-type: none"> <li>• Gold's Model of "on-line" versus "off-line" self-appraisal of risk behavior</li> <li>• Model of Relapse Prevention</li> </ul>
Popular Opinion Leader (POL)	<ul style="list-style-type: none"> <li>• Diffusion of Innovations</li> </ul>
POWER	<ul style="list-style-type: none"> <li>• Information, Motivational, and Behavioral Skills Model</li> </ul>
Project ECHO	<ul style="list-style-type: none"> <li>• Bandura's Theory of self-regulation</li> <li>• Transtheoretical Model</li> <li>• Gold and colleagues concept of self-justification for high risk sexual behaviors among MSM</li> </ul>
Think Twice	<ul style="list-style-type: none"> <li>• Conflict Theory of Decision-Making</li> </ul>
VOICES/VOCES	<ul style="list-style-type: none"> <li>• Health Belief Model</li> <li>• Theory of Reasoned Action</li> </ul>
Young Men's Health Project	<ul style="list-style-type: none"> <li>• Motivational Interviewing</li> </ul>



## Appendix D: List of PrEP Clinics in Alabama\*

<b>City</b>	<b>Clinic Name, Address, &amp; Phone Number</b>
<b>Alexander City</b>	Health Services Center - Alex City 218 South Central Ave Alexander City, AL 35010 256-832-0100
<b>Anniston</b>	Health Services Center - Hobson City 608 Martin Luther King Dr Anniston, AL 36201 256-832-0100
<b>Birmingham</b>	Birmingham AIDS Outreach 205 32nd Street S Birmingham, AL 35233 Phone: (205) 322-4197
<b>Birmingham</b>	The 1917 Clinic at UAB Community Care Building 908 South 20th Street Birmingham, AL 35294-2050 Phone: (205) 934-1917
<b>Huntsville</b>	Thrive Alabama 600 St. Clair Ave., Building 3 Huntsville, AL 35801 Phone: (256) 536-4700 Fax: (256) 536-4117
<b>Montgomery</b>	Medical AIDS Outreach 2900 McGehee Road Montgomery, AL 36111 Phone: (334) 280-3349 Toll Free: (800) 510-4704
<b>Tuscaloosa</b>	Five Horizons Health Services 2720 6th St. Tuscaloosa, AL 35401 Phone: (205) 759-8470

\*List of practices/clinics providing PrEP as of 02122018 in Alabama from Greater Than AIDS website: <https://greaterthan.org/get-prep/> & Alabama Dept of Public Health HIV/AIDS website <http://alabamapublichealth.gov/hiv/prep.html>

## Appendix E: List of PrEP Clinics and Providers in Georgia\*

<b>City</b>	<b>Clinic Name, Address, &amp; Phone Number</b>	<b>Clinic Name, Address, &amp; Phone Number</b>	<b>Clinic Name, Address, &amp; Phone Number</b>
<b>Atlanta</b>	Absolute CARE 2140 Peachtree Rd. NW Suite 232 Atlanta, GA 30309 404-231-4431	AID Atlanta 1605 Peachtree Rd. NE Atlanta, GA 30309 404-870-7762	Atlanta ID Group 275 Collier Road Suite 450 Atlanta, GA 30309 404-355-3161
<b>Atlanta</b>	Druid Hills Primary Care 1700 Briarcliff Road NE Atlanta, GA 30306 404-228-2648	Empowerment Resource Center 230 Peachtree Road NW Suite 1800 Atlanta, GA 30303 404-526-1145	Family Healthcare of Atlanta PC 1935 Howell Mill Rd NW Atlanta, GA 30318 404-355-2000
<b>Atlanta</b>	Frieda Millhouse-Jones MD - Laureate Medical Group Midtown 550 Peachtree Street NE 550 Peachtree Street NE Suite 1550 Atlanta, GA 30308 404-892-2131	Fulton County Board of Health 10 Park Place South, SE Atlanta, GA 30303 404-613-4708	Georgia Infectious Diseases 5673 Peachtree Dunwoody Road Suite 600 Atlanta, GA 30342 404-256-4111
<b>Atlanta</b>	Infectious Disease of Atlanta, LLC 735 Piedmont Ave. NE Atlanta, GA 30309 404-588-4680	Internal Medicine Specialists 1800 Howell Mill Rd. Atlanta, GA 30318 404-607-1777	Intown Infectious Disease 619 Rankin Street NE Atlanta, GA 30308 404-874-3102
<b>Atlanta</b>	Intown Primary Care 2215 Cheshire Bridge Rd Atlanta, GA 30324 404-541-0944	Intown Primary Care 730 Ponce De Leon Pl. Unit B Atlanta, GA 30306 404-541-0944	Someone Cares LGBT & Ally Resources Center 236 Forsyth Street Suite 204 Atlanta, GA 30303 678-921-2706
<b>Atlanta</b>	Southside Medical Center 1046 Ridge Avenue SW Atlanta, GA 30315 404-688-1350	Dr. T. Douglas Gurley 659 Auburn Ave NE #156 Atlanta, GA 30312 404-888-0228	
<b>Decatur</b>	Oak Grove Family Medicine 2840A Lavista Road Decatur, GA 30033 404-639-9180	Ponce Primary Care 402 Ponce de Leon Avenue Decatur, GA 30300 404-537-2521	Positive Impact Health Centers 523 Church St Decatur, GA 30030 404-589-9040

<b>Fort Valley</b>	Peach County Health Department 406 East Church Street Fort Valley, GA 31030 478-825-6939	
<b>Lawrenceville</b>	Gwinnett Clinic - Webb Gin 1289 Scenic Highway Lawrenceville, GA 30045 770-972-9000	
<b>Macon</b>	Macon Bibb County Health Department 171 Emery Highway Macon, GA 31217 478-745-0411	
<b>Marietta</b>	Someone Cares Inc. of Atlanta EDIC 1950 Spectrum Circle SE Suite 145 Marietta, GA 30067 678-921-2706	
<b>Snellville</b>	Gwinnett Clinic Snellville 2764 West Main Street Snellville, GA 30078 770-978-3388	
<b>Tucker</b>	ID Consultants, PC 1370 Montreal Road Suite 130 Tucker, GA 30084 770-939-1601	
<b>Warner Robins</b>	North Central District Houston County Health Department 98 Cohen Walker Drive Warner Robins, GA 31088 478-218-2000	

\*List of practices/clinics providing PrEP as of 02/12/2018 in Georgia from Greater Than AIDS website: <https://greaterthan.org/get-prep/>

## Appendix F: Invitation Letter

PORTIA Thomas, (DNSc), MSN-CNE, MPH

Nursing Doctoral Candidate  
Kennesaw State University  
Dissertation Research Proposal

Date

Recipient Name  
Recipient Company Name  
Recipient Address

Dear Recipient Name,

I am writing to let you know about an opportunity to participate in a research study about HIV Pre-exposure prophylaxis (PrEP) decision-making. Portia Thomas, a nursing doctoral candidate at Kennesaw State University, is conducting the study to explore men who have sex men's (MSM's) decision-making process to initiate PrEP.

I am seeking your assistance and support with recruiting participants. I understand that your first priority is patient safety and confidentiality, and I certainly agree with and respect this responsibility. Therefore, I request permission to recruit your patients by posting and providing study advertising posters and handouts in your clinic patient areas (i.e., exam rooms and waiting areas). The advertisements will have all of my contact information so interested patients can follow-up with me at their choosing.

Please review the attached study synopsis for further details. I will be following up with you in the 5-7 business days to determine your interest in assisting me with my research. If you have any questions or concerns before then, please feel free to contact me at your convenience by phone: 334-425-8516 and/or email: [pthoma48@students.kennesaw.edu](mailto:pthoma48@students.kennesaw.edu).

Thank you for considering this research opportunity.

Sincerely,

Portia Thomas

Appendix G: Study Synopsis  
**Dissertation Study Synopsis**

**TITLE:** Exploring Men who have sex with men's (MSM's) Pre-exposure Prophylaxis (PrEP) Initiation Decision-making Process

**TITLE ACRONYM:** His PrEP Decision

**Investigator's Information:** Portia Thomas, (DNSc), MSN-CNE, MPH  
Mobile: 334-425-8516  
Email: [Pthoma48@students.kennesaw.edu](mailto:Pthoma48@students.kennesaw.edu)

**Investigator's University:** Kennesaw State University in Kennesaw, GA  
URL: <http://www.kennesaw.edu/>

**Program/Department:** WellStar School of Nursing  
Doctorate of Nursing Science (DNS)

**Dissertation Committee Chairperson:** Richard Sowell, PhD, Professor  
470-578-6062  
[rsowell@kennesaw.edu](mailto:rsowell@kennesaw.edu)

**INTRODUCTION:** The MSM HIV epidemic continues to thrive in the U.S., as MSM account for majority of current and past HIV/AIDS diagnoses. MSM's HIV incidence rate is 44 times higher than in other men and 40 times higher than in women (Centers for Disease Control & Prevention [CDC], 2016b), and at this rate the CDC (2016a) estimates that 1 in 6 MSM will contract the virus in their lifetime. HIV prevention is the key to stopping MSM's current and predicted HIV incidence in the U.S. (CDC, 2016a; Fan, Conner, & Villarreal, 2014).

HIV pre-exposure prophylaxis (PrEP) is the newest HIV prevention modality, as HIV's first pharmacological prevention agent. PrEP is the fixed daily dose of Truvada in HIV-negative persons with reported and documented high HIV-acquisition risk (CDC, 2014). Clinical trial data show that in the event of an exposure, PrEP is efficacious, reducing HIV seroconversion by as much as 92% (CDC, 2014; Koenig, Lyles, & Smith, 2013). Experts estimate that PrEP initiation in at-risk groups can reduce HIV incidence by 70%, and prevent 185,000 U.S. infections by 2020 (CDC, 2016c). Each prevented HIV infection saves an estimated \$355,000 in lifetime HIV treatment (CDC, 2015). Therefore, PrEP initiation in at-risk groups can significantly change the current HIV epidemic in the U.S. and MSM population.

Most current and former PrEP patients are MSM (Krakower et al., 2015; Krakower & Mayer, 2015; Tellalian, Maznavi, Bredeek, & Hardy, 2013), but currently there is no research exploring their decision-making process to initiate PrEP. The purpose of this study is to explore PrEP initiation decision-making process of HIV-negative MSM engaging in protected and unprotected anal sex. Decision-making details what and how individuals consider and evaluate the different factors surrounding a choice or option (Poortaghi et al., 2015; Popejoy, 2005). Knowledge from this study may be a step to gauge if PrEP can have the estimated impact on the HIV epidemic and change the current MSM HIV disparity. MSM's PrEP initiation decision-making process can inform nursing practice on factors that influence PrEP decision-making and how MSM rationalize initiating PrEP based on their HIV and PrEP perceptions and understanding. With this knowledge, nurses can be able to identify opportunities to assist patients during



the decision-making process, and clarify HIV and PrEP misunderstandings and misconceptions. This study's findings can be used to educate nurses on ways to counsel and support MSM considering PrEP. This study can contribute to future development and testing of MSM PrEP initiation decision tools and interventions, which can lead to devising and implementing evidenced based strategies for achieving PrEP initiation success.

**OBJECTIVES:** The study objectives are to explore how HIV-negative MSM decide to initiate PrEP based on the evaluation and perceptions pertaining to their: (a) PrEP knowledge and HIV concern(s)/risk(s); (b) personal and social motivations to initiate PrEP; and (c) behavioral skills and abilities to adhere to PrEP.

**STUDY DESIGN:** This study will be conducted following Sandelowski's (2000, 2010) approach to qualitative description, which is rooted in naturalistic and constructivism research, used to gather, understand, and describe individuals' authentic experiences.

**SETTING:** Clinics with providers offering PrEP and PrEP services.

**DURATION OF STUDY:** Approximately 4-6 months.

**SAMPLE SIZE:** 10-30 participants

**PARTICIPANT COMPENSATION:** Participants will be compensated once with a \$30 Visa® credit gift card.

**SAMPLE SELECTION:** Participants must meet the following inclusion criteria: (a) assigned a sex of male at birth; (b) 18 years of age or older; (c) verbally confirm engagement in sex with men; (d) currently taking PrEP; (e) began taking PrEP in the past six months; (f) verbally confirm being HIV-negative; (g) read, speak, understand, and write English; and (h) provide written informed consent.

**DATA COLLECTION PROCEDURE:** Each participant will undergo one 60-minute one-on-one semi-structured interview with questions to elicit information regarding their PrEP initiation decision-making process. At the completion of the interviews, participants will complete a demographic form.



**DATA ANALYSIS PROCEDURE:** Descriptive statistics will describe the sample's demographics. Interviews will be transcribed verbatim, and will follow Elo and Kyngas' (2008) three-phase inductive content analysis process.

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Appendix H: "His PrEP Decision" Recruitment Handout

<p><b>HIS PREP DECISION RESEARCH STUDY</b></p> <p>His PrEP Decision study is recruiting research participants. The purpose of this study is to gather information on your decision to initiate PrEP. Your perspective on this will help nurses better understand this process, so we can improve how we support you &amp; future patients during this process. Read further for more information.</p>  <p><b>YOU CAN BE A PART OF THE STUDY IF YOU ARE...</b></p> <ul style="list-style-type: none"> <li>🇺🇸 A man who has sex with men</li> <li>🇺🇸 Currently taking PrEP &amp; began taking PrEP in the past 6 months</li> <li>🇺🇸 At least 18 years of age</li> <li>🇺🇸 Read &amp; speak English</li> </ul> <p><b>EXTRA STUDY DETAILS INCLUDE...</b></p> <ul style="list-style-type: none"> <li>🇺🇸 You <b>WILL</b> need to be able to give one 60-minute interview</li> <li>🇺🇸 You <b>WILL</b> receive \$30.00 compensation for your time</li> <li>🇺🇸 <b>If interested or for more information, please call (334) 425-8516.</b></li> </ul>	<p><b>HIS PREP DECISION RESEARCH STUDY</b></p> <p>His PrEP Decision study is recruiting research participants. The purpose of this study is to gather information on your decision to initiate PrEP. Your perspective on this will help nurses better understand this process, so we can improve how we support you &amp; future patients during this process. Read further for more information.</p>  <p><b>YOU CAN BE A PART OF THE STUDY IF YOU ARE...</b></p> <ul style="list-style-type: none"> <li>🇺🇸 A man who has sex with men</li> <li>🇺🇸 Currently taking PrEP &amp; began taking PrEP in the past 6 months</li> <li>🇺🇸 At least 18 years of age</li> <li>🇺🇸 Read &amp; speak English</li> </ul> <p><b>EXTRA STUDY DETAILS INCLUDE...</b></p> <ul style="list-style-type: none"> <li>🇺🇸 You <b>WILL</b> need to be able to give one 60-minute interview</li> <li>🇺🇸 You <b>WILL</b> receive \$30.00 compensation for your time</li> <li>🇺🇸 <b>If interested or for more information, please call (334) 425-8516.</b></li> </ul>
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Appendix I: "His PrEP Decision" Recruitment Poster

## HIS PREP DECISION STUDY

His PrEP Decision study is recruiting research participants. The purpose of this study is to gather information on your decision to initiate PrEP. Your perspective on this will help nurses better understand this process, so we can improve how we support you & future patients during this process.



### **YOU CAN BE A PART OF THE STUDY IF YOU ARE...**

- ✚ A man who has sex with men
- ✚ Currently taking PrEP & began taking PrEP in the past 6 months
- ✚ At least 18 years of age
- ✚ Read & speak English

### **EXTRA STUDY DETAILS INCLUDE...**

- ✚ **You WILL need** to be able to give one 60-minute interview
- ✚ **You WILL receive** \$30.00 compensation for your time
- ✚ **If interested or for more information, please call (334) 425-8516.**

## Appendix J: "His PrEP Decision" Informed Consent Form

**SIGNED CONSENT FORM**

**Title of Research Study:** Exploring Men who have sex with men's (MSM's) Pre-exposure Prophylaxis (PrEP) Initiation Decision-making Process



**Research Study Acronym:** His PrEP Decision

**Researcher's Contact Information:** Portia Thomas, DNSc, MSN-CNE, MPH  
Mobile: 334-425-8516  
Email: [Pthoma48@students.kennesaw.edu](mailto:Pthoma48@students.kennesaw.edu)

**Introduction**

The nurse-researcher, Portia Thomas, of Kennesaw State University is conducting a study. You are being invited to participate because you started taking PrEP and have identified as being a man who has sex with men (MSM). Before you decide to participate, you should read this form carefully. If you have questions regarding this consent or study, please ask at any time.

**Description of Project**

The purpose of the study is to understand how you came to the decision to start taking PrEP. The nurse-researcher wants to know the factors and process you considered that led to your decision. As a participant, you will be asked to share your story as an MSM, thoughts and concerns about HIV, and your journey to starting PrEP.

**Explanation of Procedures**

Participation in this study requires you to undergo a one-on-one 60-minute interview with the researcher. The researcher will discuss with you dates, times, and a location that makes you comfortable, and will not interfere with the nurse-researcher's ability to listen to your responses or audio-record the interview. You are the expert in PrEP initiation decision-making, so you will be asked and are encouraged to answer the questions openly and honestly. You will also be required to complete a one-page demographic form.

**Time Required**

To participate in this study, you will need to complete a one 60-minute interview with the nurse-researcher and fill out a demographic form. Therefore, the total required time for this study is approximately 65 minutes.

**Risks or Discomforts**

There are no physical or bodily risks from participating in this study. However, talking about your decision to start PrEP on a recording device may make you uncomfortable. Additionally, the interviewer will ask questions about your sexual history and behaviors and beliefs about HIV and PrEP. Discussing these topics with a female may cause you to feel uneasy or embarrassed.

**Benefits**

There are no guaranteed benefits from you participating in this study. By taking part in this study, the nurse-researcher hopes to give you a voice and opportunity to tell your story about a decision you made. Your words and responses can inform doctors and nurses about ways to improve care provided to you and other MSM PrEP patients.

**Compensation**

After you complete the interview and demographic form, you will be compensated for your time with a \$30 Visa® credit gift card.

**Confidentiality**

Protecting the confidentiality of your information is the first priority. After signing this form, you will be assigned an identification number and be asked to provide a fictional name. The fictional name is to be used during the interviews instead of your legal name. If you cannot think of a fictional name, one will be provided for you.

**Inclusion Criteria for Participation**

You must meet all of the following criteria in order to participate in this study: (a) assigned a sex of male at birth; (b) 18 years of age or older; (c) verbally confirm engaging in anal sex with men; (d) currently taking PrEP; (e) began taking PrEP in the past six months; (f) verbally confirm being HIV negative; (g) read, speak, understand, and write English, and (h) provide written informed consent.

**Signed Consent**

I agree and give my consent to participate in this research project. I understand that participation is voluntary and that I may withdraw my consent at any time without penalty.

---

Signature of Participant or Authorized Representative, Date

---

Signature of Investigator, Date

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PLEASE SIGN BOTH COPIES OF THIS FORM, KEEP ONE AND RETURN THE OTHER TO THE INVESTIGATOR

Research at Kennesaw State University that involves human participants is carried out under the oversight of an Institutional Review Board. Questions or problems regarding these activities should be addressed to the Institutional Review Board, Kennesaw State University, 585 Cobb Avenue, KH3403, Kennesaw, GA 30144-5591, (470) 578-2268.

Appendix K "His PrEP Decision" Study Enrollment Form

Consent & Enrollment Date: \_\_\_\_\_

Participant ID: PID- \_\_\_\_\_ Pseudonym: \_\_\_\_\_

**Interview Details:**

Scheduled Interview Date & Time \_\_\_\_\_

Scheduled Location \_\_\_\_\_

\_\_\_\_\_

Interview Details Confirmation Notes: \_\_\_\_\_

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**INCLUSION CRITERIA**

Circle "Yes" to confirm the patient meets the following criteria, if not circle "No"

1. Assigned a male sex at birth	Yes/ No
2. 18 years of age or older	Yes/ No
3. Verbally confirm to engage in anal intercourse (AI) with men	Yes/ No
4. Currently taking PrEP	Yes/ No
5. Began taking PrEP in the past six months	Yes/ No
6. Verbally confirm a HIV-negative status	Yes/ No
7. Read, speak, understand, and write English	Yes/ No
8. Provide written informed consent	Yes/ No

1. Does the patient meet ALL of the INCLUSION criteria? YES, or NO

If "YES" the participant is ELIGIBLE, if "NO" the participant is INELIGIBLE.

2. This participant is (circle one) INELGIBLE/ ELIGIBLE.

Research Personnel Completing Enrollment form & process please complete the area below.

\_\_\_\_\_  
Print Name

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date (mm/dd/yyyy)

**This portion of the paper was  
purposefully left blank**

## Appendix L: "His PrEP Decision "Script&amp; Interview Guide

PID-\_\_\_\_\_

Interview Date: \_\_\_\_\_

Thank you for taking the time to speak with me today. You are the expert in taking PrEP, and I need to learn from you how you came to that decision. I am interested in your story, so there is no right or wrong answer. Please share as much as you feel comfortable.

**1. How do you identify your sexuality (gay, bisexual, or MSM)? Tell me about you and your story of being and becoming aware and accepting of your identity in the South. (target 10 minutes)**

Are you open about your sexuality with family and friends? How did you decide to whom you would disclose your sexual orientation?

Tell me about your family, friends, and partners and how they affect your life.

**2. Are you sexually or romantically involved with anyone? If no, in the past 1-2 years? (target 10 minutes)**

Do you have a partner or are you married? Is this a long term or casual relationship?

Are you sexually monogamous? Did you have a discussion about being monogamous or not? Tell me about the discussion.

Do you know if your partner is HIV positive or negative? If negative, are they on PrEP?

Besides PrEP, what other protections do you take to prevent getting HIV?

Do you implement these behaviors consistently or how do you decide when or with who to take prevention precautions?

**3. Tell me about your thoughts and concerns about your HIV risks. (target 10 minutes)**

What behaviors place you at risk for getting HIV?

What are your thoughts and concerns about becoming HIV infected?

Do you know or have you met anyone with HIV?

What has been your experience with people living with HIV?

What have you heard others say about people living with HIV?

**4. Tell me how you came to know about PrEP. (target 10 minutes)**

How did you learn about PrEP? What did you think about it?

What led you to wanting to know more about PrEP?

Do you know other men who are on PrEP and what has been their experience (what have they told you about PrEP)?

How did you find your PrEP provider?

What concerns do you have about being on PrEP? (taking it every day, cost, going to the doctor every 3 months for monitoring or what other concerns you might have).

How has being on PrEP changed your sexual behaviors? Explain.

Do you feel being on PrEP has changed your risk of getting HIV? Explain how.

Do your friends, family and/or partner(s) know you are on PrEP? How do they feel about it?

**5. Tell me how you decided to start PrEP. (target 15 minutes)**

Tell me about factors or any events that made you feel PrEP would be right for you (i.e., life experiences, specific event or occurrence, your HIV risk/concerns, your understanding of PrEP).

Tell me more about the process you went through in deciding to start PrEP.

Was it an immediate decision once you learned about it or did you take a period of time to consider it?

- 6. You have given me a lot of insight into your decision-making in starting PrEP. I appreciate your willingness to share your story with me. Is there anything else you want to tell me about you or your journey to beginning PrEP? (target 5 minutes)**

**END OF INTERVIEW GUIDE**

## Appendix M: "His PrEP Decision" Demographic Form

PID- \_\_\_\_\_

Interview Date: \_\_\_\_\_

**Patient Information**

- 1) Pseudonym: \_\_\_\_\_ 2) Ethnicity (select one):  Hispanic  Non-Hispanic
- 3) Age: \_\_\_\_\_
- 4) Race (select one):  American Indian  Alaska Native  
 Asian  Black or African American  
 Native Hawaiian  Other \_\_\_\_\_  
 Pacific Islander  White
- 5) Highest education level completed (select one):  Less than high school  
 High school  
 College (associate, bachelor, or technical school)  
 Graduate school
- 6) Annual Income (select one):  less than \$20,000  \$20,001- \$40,000  
 \$40,001- \$60,000  \$60,001- \$80,000  
 more than \$80,000

7) When did you start taking PrEP? Date \_\_\_\_\_

8) Including all sexual encounters, how many sex partners have you had in the last 3 months?  
\_\_\_\_\_

Regarding the sexual encounters asked about in question 8, answer questions 9 and 10.

9) What percentage (0%-100%) of the time did you use condoms? \_\_\_\_\_

10) Which behaviors did you practice?(Check all that apply)

- 
- Anal sex (bottom)
- 
- Anal sex (top)
- 
- Oral sex (give)
- 
- Oral sex (receive)

**Please sign acknowledging that you received your \$30 Visa® credit gift card.**\_\_\_\_\_  
Participant's Pseudonym Signature\_\_\_\_\_  
Date\_\_\_\_\_  
Interviewer's Signature\_\_\_\_\_  
Date**END OF DEMOGRAPHIC FORM**

### Appendix N: Inductive Content Analysis Process

The following details the three-phase process of inductive content analysis according to Elo and Kygnas (2008).

#### **I. Preparation**

1. Read through the transcribed narratives several times to acquire a feeling and understanding of the main ideas
2. Select the unit of analysis, either a word or theme, that emerges from the narrative
3. Make sense of the data by asking: Who, what, where, when, and why regarding the content

#### **II. Organizing**

1. Begin open coding by writing notes and headings (that describe all aspects of the content) while reading through the narratives
2. The open coding process is repeated until as many as necessary headings are written down
3. The headings are transferred to coding sheets, and the headings are grouped into broader and more abstract categories
4. Abstraction follows which is naming each category using content related words
5. Perform peer checking with oversight research committee throughout this process

#### **III. Reporting**

1. To enhance trustworthiness, detail the content analysis process clearly and sufficiently
2. To improve reliability, explain the link between the data and results
3. Use actual participants' phrases and statements to show authenticity

## Appendix O: Study Recruitment Sites

<b>Clinic Name</b>	<b>City, State</b>	<b>Date Flyers Received</b>
Birmingham AIDS Outreach	Birmingham, AL	6/4/2018
The 1917 Clinic at UAB	Birmingham, AL	3/20/2018
Medical Advocacy & Outreach	Montgomery, AL	3/19/2018
Five Horizons Health Services	Tuscaloosa, AL	3/15/2018
AID Atlanta	Atlanta, GA	4/27/2018
Empowerment Resource Center	Atlanta, GA	5/24/2018
CrescentCare Health & Wellness Center	New Orleans, LA	5/11/2018
Someone Cares Atlanta	Marietta, GA	6/5/2018