Human Papillomavirus Vaccination, Online Health Information Seeking, and Health Literacy among Transgender and Gender Nonbinary People

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ABSTRACT

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BACKGROUND: Human Papillomavirus (HPV) is the most common sexually-transmitted infection in the U.S. and is associated with a number of cancers. A vaccine that can prevent 90% of HPV-associated cancers has been available since 2006, yet millions of young adults remain unvaccinated. Low vaccination uptake has been observed in cisgender sexual minority communities and less is known about HPV vaccination among transgender and gender nonbinary (TGNB) people. The aims of this dissertation were: (a) to identify facilitators for and barriers to HPV vaccination among gender minority people; (b) to compare HPV vaccination rates, HPV risk and situational factors like barriers to care, access to care, preventive care, HPV knowledge and Internet use in a sample of TGNB people and cisgender sexual minority people; and (c) to explore the association of online health information and HPV vaccination receipt among TGNB people compared to cisgender sexual minority people and determine if eHealth Literacy or general health literacy moderate this relationship.

METHODS: The dissertation comprised three studies. First, an integrative review of the literature included searches of three electronic databases to identify and appraise studies that explore patient-, provider- and system-level HPV vaccination barriers among gender minority people. Second, guided by the Integrative Model of eHealth Use, a cross-sectional secondary analysis of The **Population Research in Identities and Disparities for Equality** (PRIDE) Study Annual Questionnaire 2018-19, compared the rate of HPV vaccination among TGNB and cisgender sexual minority people and described situation factors (*e.g.*, barriers to care, access to

care, preventive care), Internet use, HPV knowledge, HPV risk, and HPV vaccination among these communities. Third, a novel cross-sectional online survey of TGNB and cisgender sexual minority participants recruited from The PRIDE Study, also guided by the Integrative Model of eHealth Use, explored the association between online health information seeking and receipt of HPV vaccine, and whether eHealth literacy and/or general health literacy moderate this relationship. Statistical methods for the cross-sectional studies included prevalence ratios (PR) using robust Poisson statistics and multivariable logistic regression with post hoc Bonferroni-Holm correction.

RESULTS: The integrative review identified six cross-sectional studies and one qualitative study that explored HPV vaccine barriers and facilitators among gender minority people. The majority of the studies included <10% gender minority participants. Key barriers to vaccination identified were misperceptions of risk at patient-level, bias towards vaccinating female assigned individuals at the provider-level and population effects of recommendations for girls-only at the policy-level. The cross-sectional secondary analysis of The PRIDE Study 2018-19 Annual Questionnaire and included N = 5,500 responses and found that: (a) the prevalence of ever receiving HPV vaccine was 1.2 times greater among TGNB participants than cisgender participants (PR 1.2; 95% CI, 1.1-1.3); (b) the prevalence of ever receiving HPV vaccine was 2.4 times greater among transgender men who were assigned female at birth compared to transgender women who were assigned male at birth (PR 2.4; 95% CI, 2.0-2.8); and (c) no differences in vaccination initiation and vaccination completion based on gender identity, sex assigned at birth, sex organs born with, or current sex organs. The cross-sectional novel online survey of PRIDE participants yielded N = 3,258 responses (response rate 19.6%). After controlling for covariates including age, race/ethnicity and educational attainment, we found that

TGNB as compared to cisgender participants had increased odds (aOR=1.5=; 95% CI, 1.1-2.2) of reporting receipt of HPV vaccine ever and decreased odds (aOR=0.7; 95% CI, 0.5-0.9) of ever receiving of HPV vaccine when they looked for info on vaccines in the past year. Conversely, TGNB participants had over twice the odds (aOR=2.4; 95% CI, 1.1-5.6) of ever receiving HPV vaccine if they visited a social networking site like Facebook or Instagram in the past year. There were no moderating effects observed from eHealth or general health literacy.

CONCLUSIONS: TGNB communities are understudied in terms of HPV vaccination and the existing literature shows misperceptions about the need of HPV vaccination among TGNB communities at both the patient and provider level. TGNB participants were more likely to have ever received HPV vaccine compared to cisgender sexual minority participants in the cross-sectional secondary analysis of The PRIDE Study 2018-19 Annual Questionnaire which may be attributed to high primary engagement in the cohort. Finally, online health information seeking about vaccines was associated with decreased receipt of HPV vaccine (ever) whereas social media use increased HPV vaccine receipt (ever) among TGNB participants compared to cisgender sexual minority participants. These conflicting findings suggest that the quality of online health information relating HPV vaccines, how, when and why TGNB people search for health information online may affect health behaviors like HPV vaccination. More research is warranted to explore how online health information seeking may influence personal health decision-making among TGNB communities.

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Dedication

This dissertation is dedicated to transgender, gender nonbinary and gender expansive people who deserve to be recognized, counted, and afforded with the opportunity to have culturally competent health care and good health.

Chapter 1: Introduction

Human papillomavirus (HPV) is the most common sexually-transmitted infection (STI) in adults in the United States with a prevalence of 79 million existing infections and incidence rate of 14 million new infections per year (Dunne et al., 2014). High-risk strains of HPV (type 16 & 18) are associated with 79% of anal cancers, 66% of cervical cancers, 62% of oropharyngeal cancers, and 55% vaginal cancers (Centers for Disease Control and Prevention, 2013; Dunne et al., 2014). A vaccine to prevent HPV infection was introduced in 2006 and was initially recommended only for girls, with a 2-dose series from age 9 through 15 years, and a 3-dose catch-up series from age 16 through 26 years. The recommendation was expanded to boys in 2009 and men who have sex with men (MSM) in 2011 (Markowitz et al., 2014; Petrosky et al., 2015). The national goal proposed in Healthy People 2020 targeted 80% vaccine completion for HPV (*i.e.*, received the full vaccination series) (Markowitz et al., 2014). However, the Centers for Disease Control and Prevention (CDC) now estimates that only fifty-one percent of eligible adolescents have achieved vaccine completion and approximately 23 million young adults remain unvaccinated for HPV in the general population (Walker et al., 2017; Williams et al., 2017). In June 2019, the CDC Advisory Committee on Immunization Practices (ACIP) expanded the recommended age range from 9 through 26 years to 9 through 45 years for both women and men (Meites, 2019).

Low HPV vaccine completion (13 to 32%) has been observed in adult sexual minority populations defined by their sexual orientation *i.e.*, gay men, lesbian women, bisexual men and women (Agenor, Peitzmeier, et al., 2016; McRee et al., 2014; Reiter et al., 2015; Williams et al., 2017). Studies have identified lack of knowledge or trust in vaccines, non-disclosure of sexual identity to providers, and fear of discrimination/stigma as barriers to HPV vaccination in sexual minority people (Barefoot et al., 2017; Cummings et al., 2015; Gerend, Madkins, Phillips,

Mustanski, et al., 2016; McRee et al., 2014; Youatt, 2017). Less is known about HPV vaccination among gender minorities known as transgender and gender nonbinary (TGNB) people, who are estimated to number at least 1.4 million in the U.S (Flores, 2016). Unlike cisgender sexual minority people whose gender identity matches their assigned sex at birth, TGNB people have gender identities/expressions that may not conform to their assigned sex at birth and may self-identify as transmen / transwomen, transgender men / transgender women or men / women (American Psychological Association, 2015; Institute of Medicine, 2011). Some TGNB people self-identify as nonbinary or genderqueer, terms used to describe people whose gender is not exclusively male or female, including those who identify with a gender other than male or female, as more than one gender, or as no gender (James, 2016). For the purposes of this dissertation, we use the terms transgender and gender nonbinary (TGNB) to encompass these communities, however we acknowledge that TGNB may not capture all that ways in which gender minority people express their identities. As gender identity and gender expression continue to evolve, we are committed to acknowledging and describing the gender-expansive diversity of gender minority people. Sexual and Gender Minorities (SGM) were designated a Health Disparities Population (HDP) for research purposes by the National Institutes of Health (NIH) in recognition of the health disparities and unique health challenges that face these communities (Pérez-Stable, 2016).

Problem Statement

The true proportion of adult TGNB and cisgender sexual minority people who have not received any doses of HPV vaccine is likely higher than the general population given studies to-date (Agenor, McCauley, et al., 2016; Agenor et al., 2015; Agenor, Peitzmeier, et al., 2016; Charlton et al., 2017; McRee et al., 2014; Reiter et al., 2015). TGNB people report a higher

prevalence of poor health and experience stigma and discrimination with healthcare providers based on their gender identity, resulting in poor health outcomes from delaying or deferring necessary care (Bockting et al., 2013; Bradford et al., 2013; Jaffee et al., 2016; Macapagal et al., 2016; Meyer et al., 2017; Safer et al., 2016; Winter et al., 2016). For example, TGNB people with a cervix and are sexually active are at risk of HPV infection, yet they have reduced rates of cervical cancer screening and increased time between recommended screening intervals compared to cisgender women (Peitzmeier, Khullar, et al., 2014; Peitzmeier, Reisner, et al., 2014).

There have been few studies that focus on HPV vaccination among TGNB people. A small study of rural-residing TGNB people noted a variation in HPV vaccination initiation (*e.g.*, received at least one HPV shot); the greatest proportion 62.1% (n = 18) who initiated were transgender nonbinary people assigned female at birth, followed by transmen 36.6% (n = 15), nonbinary people assigned male at birth 20% (n = 1), and the smallest proportion initiating vaccination were transwomen 5.3% (n = 1) (Bednarczyk et al., 2017). Although this research also noted a significant association between healthcare provider recommendation and receipt of a HPV vaccine shot, the study's small sample size limits its generalizability (Bednarczyk et al., 2017). Studies among cisgender sexual minority people have similarly shown a positive association between provider recommendation and HPV vaccination (Gerend, Madkins, Phillips, Mustanski, et al., 2016; Gorbach et al., 2017; McRee et al., 2014). However, new research suggests that independent of healthcare providers, individuals who encounter cultural barriers to accessing care are more likely to seek health information online (Perez et al., 2016).

Studies using data from the Health Information National Trends Survey (HINTS) found that sexual minority people are more likely to seek health information online, more likely to

watch health videos online, and less likely to first seek health information from a physician compared to heterosexual people (Jabson et al., 2017; Langston et al., 2019; Lee et al., 2017). TGNB people have particularly unique health information needs relating to their gender identity such as gender-affirming hormone management (Horvath et al., 2012; Perez et al., 2016). Although TGNB people have been shown to utilize the Internet for community building and information sharing, there is a paucity of research that explores online health information seeking among TGNB people and how this may be associated with personal health decision-making such as whether to receive preventative care like HPV vaccination (Shapiro, 2004).

Purpose of Dissertation

The purpose of this dissertation is to examine HPV vaccination in U.S.-based adult TGNB people (age ≥18 years). As part of the dissertation, we conducted a series of studies using participants in an online U.S.-based longitudinal study of SGM people, The Population Research in Identities and Disparities for Equality (PRIDE) Study. The PRIDE Study is a large national cohort composed of over 18,800 SGM people since its launch in May 2017 (Lunn, Capriotti, et al., 2019; Lunn, Lubensky, et al., 2019; The PRIDE Study, 2019).

Specific Aims

The proposed dissertation seeks to generate new knowledge about HPV vaccination among TGNB people. To achieve this goal, we propose three study aims described in Table 1.1.

Significance

HPV represents considerable cost and disease burden. HPV is estimated to have a direct medical cost in-excess of $1.7 billion in the U.S. HPV is a STI that is thought to be acquired soon after initiating sexual activity. HPV infection can cause genital warts but could also develop into cancer depending on the site of infection (Satterwhite et al., 2013). The average number of HPV-related cancers diagnosed annually is estimated to be >33,000 (Saraiya et al., 2015; Viens et al., 2016). Research on the burden of HPV infection has disproportionately focused on cervical cancer in women (Bowyer et al., 2014; Crosbie et al., 2013). However, incidence is now increasing for HPV-related oropharyngeal and anal cancers. Recent studies have shown that the incidence of HPV-related oropharyngeal cancer in men has increased dramatically, now surpassing the rate of cervical cancer in women, and the incidence of anal cancer has doubled over that past two decades (D'Souza et al., 2017; Machalek et al., 2012; Sonawane et al., 2017; Stier et al., 2016).

SGM people are at risk of HPV infection and HPV-related cancers. Although HPV is thought to be a highly prevalent in the general population, studies have shown increased risk of HPV infection among SGM people including increased rates of oropharyngeal, cervical, and anal HPV infection (D'Souza et al., 2017; Forner et al., 2018; Machalek et al., 2012; Singh et al., 2019). A recent study found that the prevalence of anal HPV infection was 1.3 times greater for transgender women than cisgender men who have sex with men, or MSM (PR 1.3; CI 95%, 1.1 – 1.4) (Singh et al., 2019). Higher rates of anal HPV infection have been observed among

HIV-positive MSM compared to HIV-positive heterosexual cisgender men (Patel et al., 2018). Anal cancer rates have been shown to be 80 times higher in HIV-positive MSM compared to HIV-negative MSM (Silverberg et al., 2012). High rates of HIV-infection have been observed among TGNB people which is thought to increase their risk of HPV-associated cancer (Poteat et al., 2016; Quinn et al., 2015).

Cisgender sexual minority people and TGNB people may experience unique barriers to vaccination. Studies to date that explore HPV vaccination barriers have focused primarily on cisgender minority individuals. Yet, TGNB people often experience similar barriers to healthcare as cisgender sexual minority people (Cruz, 2014; Edmiston et al., 2016). All SGM people may experience increased fear of discrimination and stigma from healthcare providers, and these pose a barrier to obtaining HPV vaccination (Barefoot et al., 2017; Cummings et al., 2015; Meyer, 2003). Similarly, individuals who fear discrimination may not disclose their sexual identity to healthcare providers, which has also been observed to be a significant barrier to preventive vaccination (Gerend, Madkins, Phillips, Mustanski, et al., 2016; Wheldon et al., 2017; Youatt et al., 2017). Lack of HPV and vaccine knowledge is a known barrier to vaccination, and studies have shown that TGNB people and cisgender MSM may be unaware that HPV vaccination is recommended for both men and women (Apaydin, Fontenot, Shtasel, et al., 2018; Wheldon et al., 2017).

HPV vaccination is effective when the recommended 3-dose vaccine series is completed; however, studies have not always assessed number of doses. The first HPV vaccine protected against four strains of HPV when it was introduced in 2006 and was updated in 2014 to protect against nine strains (McNamara et al., 2016). The vaccine has been shown to be highly effective, with one analysis of a national probability sample demonstrating a 61% reduction in prevalence

in HPV infection in adult females age 20-24 years within eight years of vaccine introduction (Oliver et al., 2017). Another analysis projects a 90% reduction of HPV-associated cancers through vaccination (Saraiya et al., 2015). Studies have shown that adults who receive only one dose of the vaccine are not fully protected from HPV infection, whereas three-doses provides immunity and prevents HPV-related cancers (Kang et al., 2018). Studying vaccination initiation versus completion is important for understanding HPV risk, yet previous studies often neglect to report number of doses, representing a critical gap in knowledge (Fuller & Hinyard, 2017; Oliver, 2017).

Cisgender sexual minority people have decreased rates of HPV vaccination initiation and completion compared to the general population, but less is known about TGNB people. Disparities in HPV vaccination rates have been investigated among cisgender sexual minority people. A study using a national sample of gay and bisexual men (age 18-26 years) found that only 13% (*n = 428*) of the sample received at least one-dose of the HPV vaccine (Reiter et al., 2015). Another study using a national sample of lesbian and bisexual women (age 18-26 years) found that 45% (*n = 543*) of subjects received at least one dose of the HPV vaccine (McRee et al., 2014). Others have investigated disparities in vaccination rates among cisgender sexual minority people that provide a more nuanced view. For example, a study found that bisexual women were significantly more likely than heterosexual women to have initiated the HPV vaccination series but were significantly less likely to complete the series, lesbian women were no more likely to initiate vaccination but were less likely to complete the series than heterosexual individuals (Agenor et al., 2015). These findings suggest the possibility that vaccination initiation/completion rates could also differ within TGNB sub-groups, e.g., transgender men,

transgender women, and transgender nonbinary people depending on assigned sex at birth (Bednarczyk et al., 2017).

Theoretical Model

The Integrative Model of eHealth Use (IMeHU) by Bodie & Dutta guides this dissertation (Bodie & Dutta, 2008). This model proposes a framework (Figure 1.1) to understand the relationship between electronic health use and health behavior outcomes. It posits that orientation to online health information is associated with health behavior outcomes, and that this relationship is influenced by individual factors such as situation, health knowledge and beliefs, general health literacy, and electronic health literacy (Bodie & Dutta, 2008). This theoretical framework is particularly useful for this dissertation because it considers individual factors such as demographics as well as individual situational factors such as barriers to care, access to care, preventive care, and health knowledge/beliefs. The IMeHU has not previously been applied to study health information seeking among TGNB people.

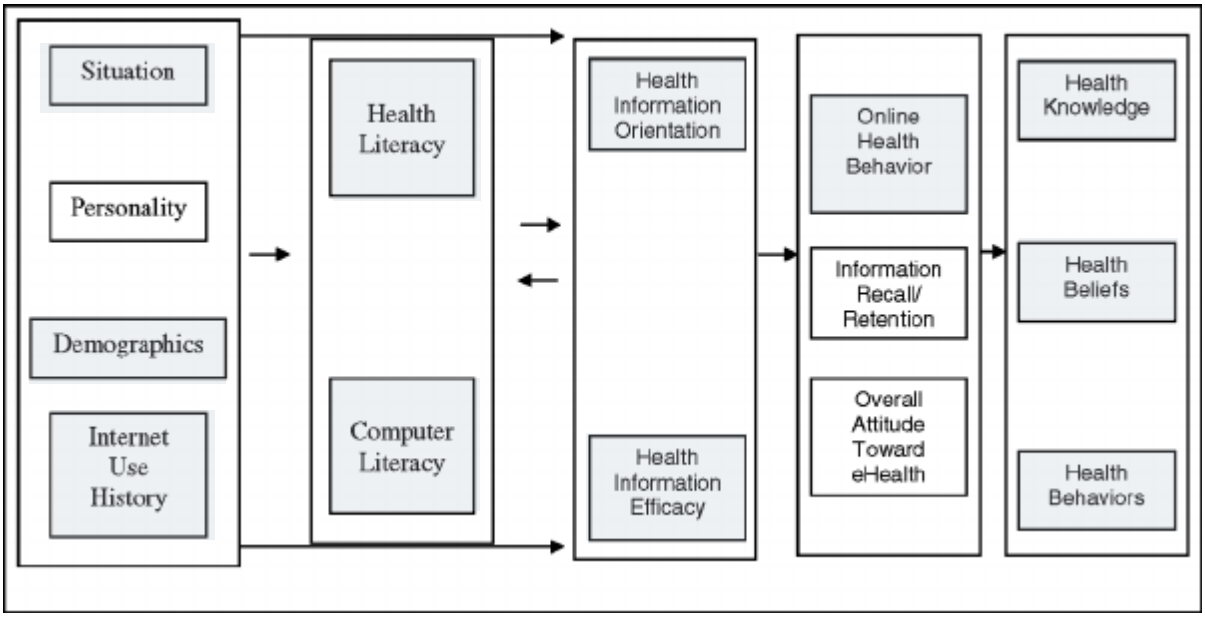

Figure 1. 1 Integrative Model of eHealth Use (Bodie & Dutta, 2008)

[Shaded areas denote constructs that were operationalized in the adapted model]

We adapted the model (Figure 1.2) such that the model construct known as health information orientation, or motivation to seek health information and online health behavior are combined and operationalized as general and online health information seeking, and these become the primary predictors of interest. Health literacy, computer literacy and health information efficacy in the original model are operationalized in the adapted model as general health literacy and electronic health literacy (eHealth) literacy, and these are hypothesized to moderate the effect of health information orientation on the health behavior outcome; HPV vaccination initiation and completion. In addition to the main predictors, general and online health information seeking, the adapted model also proposes additional individual factors as predictors. These encompass **health knowledge/beliefs** (*e.g.*, heard of HPV vaccine), **demographics** (*e.g.*, gender identity), **Internet use** (*e.g.*, social media use), and additional situation factors that broadly include **barriers to healthcare** (*e.g.*, delayed/not received care, avoiding care anticipating of provider discrimination/stigma, level of disclosure of of sexual

orientation and/or gender identity to provider), **preventive care** (*e.g.*, receipt of other preventive vaccinations, and **access to care** (*e.g.*, having a primary care provider). The original constructs in the Integrative Model of eHealth Use and how they are operationalized in our adapted model are summarized in Table 1.2. The operationalization of the adapted model, including specific variables and instruments is described in further detail in Chapter 4 and Chapter 5.

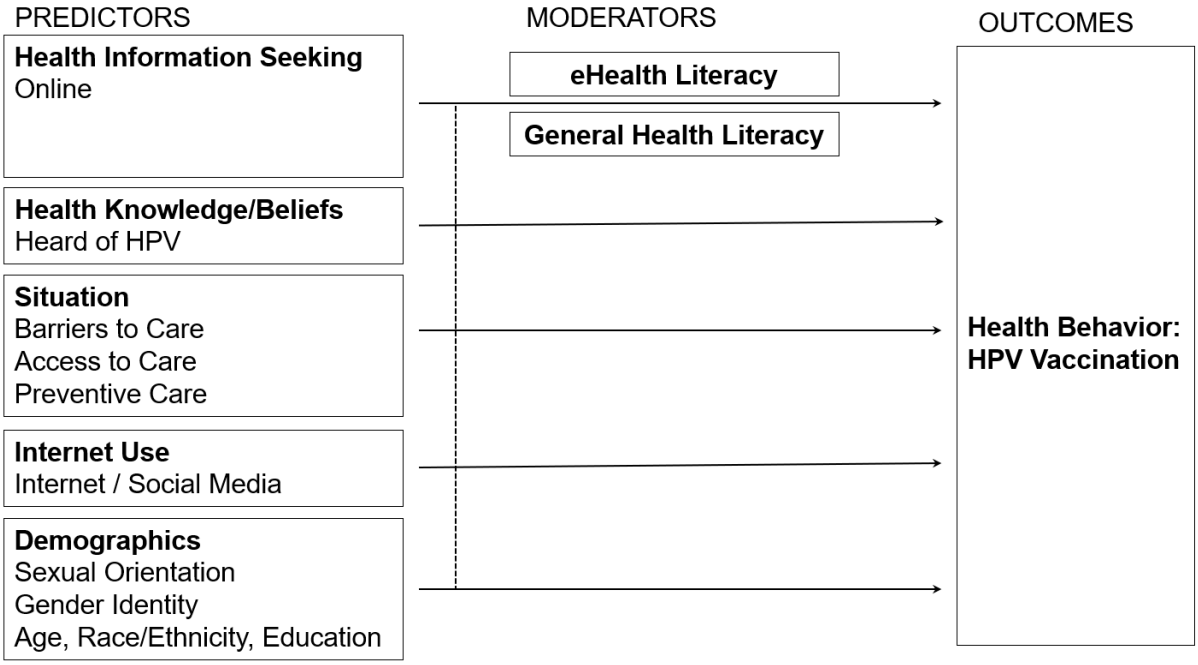

Figure 1. 2 Adapted Integrative Model of eHealth Use (IMeHU)

Online health information seeking has not been explored among TGNB people. Yet, online health information seeking has the potential to be an important individual factor for the study of health behavior, especially in today's increasingly connected world. The Pew Center estimates that 77% of people in the U.S. now own a mobile smartphone making mobile Internet access nearly ubiquitous (Pew Research Center, 2018). Internet use has been described among TGNB people but not the relationship between online health information seeking and health behavior such as vaccination (Evans et al., 2017; Patel et al., 2016; Sun et al., 2016; Wigfall & Friedman, 2016). Health information seeking is generally understood as the ways in which individuals obtain information about their health, health promotion, risks, and illness (Lambert & Loiselle, 2007). Studies in MSM have shown increased likelihood of HPV vaccination in individuals who searched online for sexual health information and increased perceived benefits of vaccination in those with higher levels of motivation to seek heath information (Stupiansky et al., 2017; Wheldon, Daley, et al., 2018). Given the unique healthcare needs of TGNB people, these communities may be more likely seek health information online in order to make up for knowledge deficits in their health care providers, or simply to avoid discrimination related to their gender identity that they may encounter in health care (Mayer et al., 2008; Wylie et al., 2016).

Electronic health literacy is another individual factor that has not been studied among TGNB people. Health literacy is understood as a person's ability to understand and process health information to make health decisions (Institute of Medicine, 2004). The National Assessment of Health Literacy reported that over 75 million adults combined had basic and below basic health literacy (Cutilli & Bennett, 2009). Low health literacy is associated with a wide range of poor health outcomes such as increased HIV risk, incorrect medication usage, and

decreased preventive cancer screening such as cervical Pap smears (Berkman et al., 2011). Complicating matters further, healthcare information is increasingly digital, requiring electronic health literacy (eHealth literacy) that encompasses a new set of knowledge, skills, and understanding of technology in order to make healthcare decisions (Norman & Skinner, 2006). To date, there has been no study of eHealth literacy specific to TGNB people although eHealth literacy has been studied among cisgender sexual minority people using the eHealth Literacy Scale (Blackstock et al., 2016; Horvath & Bauermeister, 2017; Norman & Skinner, 2006). Moreover, we apply the Integrative Model of eHealth Use as a novel approach to study of eHealth literacy as a moderator between health information orientation and a health behavior (HPV vaccination) among TGNB people.

Summary

A significant knowledge gap exists regarding HPV vaccination among TGNB people. Previous research of HPV vaccination has demonstrated decreased HPV vaccination among cisgender sexual minority people but with inconsistencies in the rigor of their approach, particularly the omission of number of vaccine doses which is critical for characterizing HPV risk (Agenor et al., 2015; Fuller & Hinyard, 2017; McRee et al., 2014; Oliver, 2017; Reiter et al., 2015). Moreover, there has been limited research that explores vaccination among TGNB people (Bednarczyk et al., 2017). This dissertation proposes to address some of the deficiencies of the prior research and generate new knowledge about HPV vaccination among TGNB people with the goal of informing future interventions to improve HPV vaccine uptake among these communities.

Table 1. 1 Specific aims of dissertation

Aim	Description	Hypotheses	Method	Chapter
1	Conduct an integrative review of the literature to identify facilitators for and barriers to HPV vaccination in gender minority people.		Integrative Review of the Literature	Ch 2
	a. Identify barriers and facilitators that influence HPV vaccination among adult gender minority people			
2	Describe HPV vaccination rates, HPV risk and situational factors (barriers to care, access to care, preventive care) in a sample of participants from a national cohort of SGM people.		Secondary Analysis	Ch 3 Ch 4
	a. Compare HPV vaccination initiation / completion rates among adult TGNB and cisgender sexual minority people	a. TGNB people have lower rates of HPV vaccination initiation and completion compared to cisgender sexual minority people		
	b. Compare prevalence of HPV risk activities in adult TGNB and cisgender sexual minority peoples	b. TGNB people have similar rates of HPV risk activities as cisgender sexual minority people		
	c. Compare HPV knowledge, situation factors (barriers to care, access to care, preventive care) and Internet use among adult TGNB and cisgender sexual minority people	c. TGNB people report similar knowledge of HPV, increased barriers to care, reduced access to care, reduced preventive care and similar Internet use compared to cisgender sexual minority people		
3	Explore factors associated with HPV vaccination initiation/completion among TGNB people, particularly online health information seeking and eHealth literacy, by an online survey of participants recruited from The PRIDE Study		Prospective Survey	Ch 3 Ch 5

Aim	Description	Hypotheses	Method	Chapter
	a. Explore the association of online health information seeking, health knowledge/ beliefs, situation factors (barriers to care, access to care, preventive care), and Internet use with HPV vaccination	a. Online health information seeking behavior, health knowledge/beliefs, situation, and Internet use are all associated with HPV vaccination		
	b. Determine if general and electronic health literacy moderate the association between online health information seeking and HPV vaccination	b. Online health information seeking behavior is associated with vaccination and electronic health literacy and general health literacy moderate the association		

Table 1. 2 IMeHU adapted constructs

Adapted Construct	Original Construct(s)	Variable Type	Instrument(s)
Health Information Seeking	Health Information Orientation Online Health Behavior	Predictor	Health Information National Trends Survey (HINTS) adapted items
Health Knowledge/ Beliefs	Health Knowledge/ Beliefs	Predictor	PRIDE Study items
Situation	Situation	Predictor	PRIDE Study items
Demographics	Demographics	Predictor	PRIDE Study items
Internet Use Social Media Use	Internet Use History	Predictor	The PRIDE Study items HINTS items
General Health Literacy	Health Literacy Health Information Efficacy	Moderator	Chew, et al. adapted discrete items
eHealth Literacy	Health Literacy Health Information Efficacy Computer Literacy	Moderator	Electronic Health Literacy Scale (eHEALS)
Health Behavior Outcomes	Health Behaviors	Outcome	HPV vaccination (ever) and number of doses

Chapter 2: Human papillomavirus vaccination among gender minority people: an integrative review of the literature

The study in Chapter Two addresses the first aim of the dissertation in an integrative review to explore barriers to and facilitators for human papillomavirus (HPV) vaccination among transgender and gender nonbinary (TGNB) people.

Introduction

Human papillomavirus (HPV) is the most common sexually-transmitted infection (STI) in adults in the United States with a prevalence of 79 million existing infections and incidence rate of 14 million new infections per year (Dunne et al., 2014). High-risk strains of HPV (type 16 & 18) are associated with the majority of oropharyngeal, vagino-cervical, and ano-rectal cancers (Centers for Disease Control and Prevention, 2013; Dunne et al., 2014). A preventive vaccine was introduced in 2006, initially only recommended for girls, with a 2-dose series from age 9 through 14 years, and a 3-dose catch-up series from age 15 through 26 years. The recommendation was expanded to boys in 2009 and men who have sex with men in 2011 (Markowitz et al., 2014; Petrosky et al., 2015). Healthy People 2020 set a national target goal for 80% vaccination completion in adolescents (Markowitz et al., 2014). However, current vaccine completion is approximately 54.2% among eligible adolescents in the general population and the Centers for Disease Control and Prevention (CDC) estimates that as of 2015, approximately 23 million young adults remain unvaccinated (Elam-Evans et al., 2020; Williams et al., 2017). In June 2019, the CDC Advisory Committee on Immunization Practices expanded the recommended age range from 9 through 26 years to 9 through 45 years for both women and men (Meites, 2019).

Low rates of 3-dose vaccine completion (range 13-32%) have been observed in adult sexual minority people defined by their sexual orientation (*e.g.*, gay men, lesbian women, bisexual men and women) (McRee et al., 2014; Reiter et al., 2015; Williams et al., 2017). Studies have identified lack of knowledge or trust in vaccines, non-disclosure of sexual identity to providers, and fear of discrimination/stigma as barriers to vaccination in sexual minorities (Barefoot et al., 2017; Cummings et al., 2015; Gerend, Madkins, Phillips, Mustanski, et al., 2016; McRee et al., 2014; Youatt, 2017). Less is known about HPV vaccination in adult gender minority people that include transgender and gender-expansive people who are estimated to number 1.4 million in the U.S. (Flores, 2016). In contrast to cisgender people, whose gender identity is consistent with their sex at birth, gender minority people have a gender identity or gender expression that differs from that commonly associated with their sex assigned at birth (Institute of Medicine, 2011). Gender minority people report a higher prevalence of poor health and experience stigma and discrimination with healthcare providers based on their gender identity, resulting in poor health outcomes from delaying or deferring necessary care like vaccination (Bradford et al., 2013; Jaffee et al., 2016; Macapagal et al., 2016; Meyer et al., 2017; Safer et al., 2016; Winter et al., 2016). Moreover, gender minority people who have a cervix and are sexually active are at risk of HPV and yet have reduced rates of cervical cancer screening and increased time between recommended screening intervals compared to cisgender women (Peitzmeier, Khullar, et al., 2014; Peitzmeier, Reisner, et al., 2014). Sexual and gender minority (SGM) people were designated a health disparities population for research by the National Institutes of Health in recognition of poor health outcomes in these communities (National Institutes of Health, 2019).

The true proportion of adult sexual and gender minority people who have not received any doses of HPV vaccine is likely higher than the general population (Agenor, McCauley, et al.,

2016; Agenor et al., 2015; Agenor, Peitzmeier, et al., 2016; Charlton et al., 2017; McRee et al., 2014; Reiter et al., 2015). We used the integrative review framework proposed by Whittemore & Knafl (2005) to organize our review which includes the following components: problem identification, literature search strategy, data evaluation, data analysis, and synthesis of findings.

Problem Identification

This integrative review seeks to describe barriers to and facilitators for HPV vaccination in adult gender minority people. We use the social ecological model to guide this review. This model has been adopted in numerous settings and is helpful for framing an investigation about vaccination because it considers how an individual's health behavior may be influenced by intrapersonal, interpersonal, institutional, community, and policy-level factors (McLeroy et al., 1988). We adapt this multi-level view of health behavior to three ecological levels: patient-level (intrapersonal); provider-level (interpersonal); and systems-level (institutional/ community/ policy).

Methods

Data Sources and Literature Search Strategy

The literature search strategy included a computer search, review of reference lists from retrieved articles, and hand-searching using Google Scholar to identify additional articles. The computer search included three databases: PubMed/MEDLINE, Cumulative Index of Nursing and Allied Health Literature (CINAHL), and EMBASE. Searches were performed November through December 2019. Citations were organized and sorted using EndNote® version X8.2 software (Clarivate Analytics, Inc, Philadelphia, PA). Keywords were explored from the following categories: sexual and gender minority communities, HPV vaccination, and keywords pertaining to vaccination barriers and facilitators.

We included both sexual and gender minority keywords to decrease the possibility of omitting a study that included gender minority people. Literature searches pertaining to sexual and gender minority populations are challenging because several terms can be used to describe lesbian, gay, bisexual and transgender (LGBT) people. Lee, et al. (2016) investigated this issue in a systematic review and identified eight search terms for transgender individuals alone. The query including keywords and Boolean logic suggested by Lee et al. (2016) informed our search strategy. The final query was formatted for PubMed/MEDLINE using medical subject headings (MeSH) terms and was simplified to comply with the controlled vocabularies for each database. A full description of the keywords and query for each database is described in Appendix A.

Eligibility Criteria

We included studies that examined factors associated with HPV vaccination in adult gender minority communities, both quantitative and qualitative study designs, abstracts and full-text articles. Studies were included if the sample population included exclusively gender minority people, or both sexual minority people and gender minority people. We excluded studies that reported only HPV vaccine prevalence without mention of barriers or facilitators. Non-English language studies and non-U.S. based studies were excluded as we wished to focus on the experience of gender minority people in the U.S. We excluded studies that focused exclusively on adolescent/pediatric populations age <18 years because of the difference in healthcare decision-making agency involving a parent/guardian compared to an independent adult.

Data Screening & Extraction

First, the initial database query results were entered into EndNote and de-duplicated using the Bramer de-dupe method (Bramer et al., 2016). Two reviewers (AP and SM) then used

Covidence software (Covidence Ltd., Melbourne, Australia) to identify any additional duplicates and proceed with the screening. Reviewers independently screened citations by title and abstract using the inclusion/exclusion criteria. The same criteria were re-applied to the full-text review. Disagreements were discussed and resolved at each phase of screening.

Methodological Quality Appraisal of Studies

There exists no gold standard for quality appraisal in an integrative review and the process of evaluating quality is complex (Whittemore & Knafl, 2005). The quantitative studies were evaluated with an 8-item quality checklist published by the Joanna Briggs Institute (JBI) (Johanna Briggs Institute, 2018). The two reviewers performed quality appraisal for the quantitative studies independently and then met to discuss and resolve any differences. The single qualitative focus group study was evaluated by a single-reviewer (AP) for qualitative rigor with narrative criterion proposed by Wu et al (2016).

Data Extraction and Synthesis

The primary author reviewed and extracted key results from each study. The data extraction process approach included 1) data reduction, 2) data display 4) data comparison, 4) conclusion drawing and verification (Whittemore & Knafl, 2005). We used the social ecological model to organize the study results into patient-, provider-, and policy-level findings and synthesize these into barriers to and facilitators for HPV vaccination. This data extraction step was performed by one author (AP).

Data Analysis

The data analysis included all studies that met the inclusion/exclusion criteria regardless of methodological rigor. This enabled the incorporation of as many perspectives as possible on barriers to and facilitators for vaccination. The data for barriers to and facilitators for preventive

vaccination among SGM people were analyzed *a priori* according to the social ecological model categories: patient-level (intrapersonal), provider-level (interpersonal), and system-level (institutional/community/policy). Data analysis included the following steps suggested by Whittemore & Knafl (2005): first data were reduced according to sub-categories and then extracted into a matrix to organize them into a manageable framework; the extracted data was converted into data display in the form of tables; the display data was compared to identify meaningful patterns; findings synthesized into summary conclusions.

Results

Database Search Results

Searches of the three databases returned 514 citations and hand-searching for citations using reference lists and yielded four citations. After removing duplicates (*n* = 191), the number of studies was reduced to 327. Articles were then screened by title and abstract and after the inclusion/exclusion criteria was applied, 278 articles were excluded from the following reasons: non-U.S. study (*n* = 134), described HPV disease/treatment only (*n* = 76), clinical or systematic review article (*n* = 26), described vaccine cost-effectiveness only (*n* = 22), described other testing and/or vaccine other than HPV (*n* = 13), no SGM people included in the sample (*n* = 6), and conference abstract with full-text unavailable for review (*n* = 1). The remaining 49 studies were screened by full-text review involving line-by-line reading of each study. After inclusion/exclusion criteria were applied again, 41 studies were excluded for the following reasons: no gender minorities included in the study sample (*n* = 39), study described vaccine prevalence rates only (*n* = 3). We retained seven studies for the integrative review. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (*PRISMA*) guidelines flow diagram that describes the article search and selection process is documented (Figure 1).

Of the retained studies, six were cross-sectional design (Apaydin, Fontenot, Borba, et al., 2018; Bednarczyk et al., 2017; Fontenot et al., 2016; Gorbach et al., 2017; Halkitis et al., 2019; Singh et al., 2019), and one a qualitative focus group design (Apaydin, Fontenot, Shtasel, et al., 2018). Two of the cross-sectional studies employed electronic health record (EHR) data (Apaydin, Fontenot, Borba, et al., 2018; Fontenot et al., 2016), three studies employed in-person computer assisted interview (CASI) (Gorbach et al., 2017; Halkitis et al., 2019; Singh et al., 2019), and one study employed an Internet-based online survey (Bednarczyk et al., 2017).

Inclusion of Sexual Minority People

None of the studies included gender minorities exclusively and five of the seven studies had samples with < 10% gender minority people (Apaydin, Fontenot, Shtasel, et al., 2018; Fontenot et al., 2016; Gorbach et al., 2017; Halkitis et al., 2019; Singh et al., 2019). The two studies with the highest proportion of gender minorities, Apaydin et al. (2018) and Bednarzcyk et al. (2017) were the most gender-diverse, including participants that identified as gender non-binary or genderqueer; gender identifications used by gender minority people whose gender expression is not exclusively masculine or feminine (Institute of Medicine, 2011). The cross-sectional study by Apaydin et al. (2018) had the highest gender minority total (n = 77, 26.9%), transmasculine / transman (n = 41, 14.9%), transfeminine/transwoman (n = 33, 12%), and of these some also identified as genderqueer (n = 17, 6.2%). Bednarcyzk et al. (2017) had gender minority total (n = 106, 16.1%), transwoman (n= 23, 3.5%), and transman (n = 46, 7.0%), and non-binary identified (n = 37, 5.7%). Four studies had both transgender men and women, including the qualitative and cross-sectional studies by Apaydin et al. (Apaydin, Fontenot, Borba, et al., 2018; Apaydin, Fontenot, Shtasel, et al., 2018), and the studies by Bednarczyk et al. (2017) and Fontenot et al. (2016). The studies by Gorbach et al. (2017) and Singh et al. (2019)

included only transgender women. The study by Halkitis et al. (2019) included transgender people (n = 33, 6.8%) but did not further specify their gender identity. With the exceptions of Bednarczyk et al. (2017), the qualitative study by Apaydin et al. (2018), and the study by Singh et al. (2019), the other studies did not distinguish between gender minorities and sexual minorities in their results.

Quality Appraisal

To add further rigor to the review, we performed a two-reviewer quality appraisal of the evidence using a standardized instrument (Johanna Briggs Institute, 2018). The quality of the cross-sectional studies was high with a mean score of 7.2 out of 8. All studies met at least six of the eight JBI quality criteria. The most common methodological deficit was lack of consideration for confounders. The quality appraisal for the cross-sectional studies is summarized on Table 2.2. One reviewer (AP-only) appraised the quality of the single qualitative focus group study by Apaydin et al. (2018) using a using narrative criterion for qualitative rigor proposed by Wu et al. (2016), including credibility, dependability, confirmability, transferability, trustworthiness and transparency. The study had no major quality concerns, but rigor would have been improved with additional description of the theoretical basis for the thematic content analysis. Trustworthiness and transparency would have been improved with more description of audit trails during and after the focus groups and whether-or-not member checks with participants were performed.

Vaccination Barriers.

Patient-level. The most frequently cited patient-level barrier to vaccination was lack of knowledge of HPV, HPV risk and the HPV vaccine. Apaydin et al. explored this in a focus group of SGM people (Apaydin, Fontenot, Shtasel, et al., 2018). Transgender women were unaware of

the risks associated HPV-infection in the context of transfeminine bodies and some had the misconception that HPV vaccine was not relevant depending upon sexual activity before or after gender affirmation surgery. Singh et al. (2019) also found that less than half (*n* = 23, 46.9%) of transgender women in their study were aware that there is a vaccine that can protect against certain types of HPV and only one in four (*n* = 12, 24.5%) transgender women were aware that HPV can cause throat and oral cancer. Gorbach et al. (2017) found that lack of knowledge extended to not knowing where to get the vaccine and concerns over safety of vaccines, but these patient-level barriers were not specific to transgender participants. Apaydin et al. (2018) noted a unique personal-level barrier expressed by a transgender woman who had to weigh their anxiety about being in public as a transgender person with the need for multiple visits for the shots. All SGM participants viewed long time intervals between doses, multiple doses, and inconvenience of work conflicting with appointment hours as additional barriers to vaccination. Fontenot et al. (2016) found that transgender males had 62% lower odds of HPV vaccination compared with cisgender females, however specific barriers related to trans men in the study were not identified. Additional patient-level barriers to vaccination included lower education attainment and presence of substance use disorders in a mixed SGM sample (Apaydin, Fontenot, Shtasel, et al., 2018).

Provider-level. Bednarczyk et al. (2017), examined the association between provider recommendation and vaccination and found that providers recommended HPV vaccination less to individuals with male sex assigned at birth (*n*= 53, 17%), regardless of their gender identity and these individuals received at least one-dose of the vaccine (*n*= 40, 13.7%), less frequently than individuals with female sex assigned at birth who were recommended to get the HPV vaccine more frequently (*n*= 146, 47.2%), and subsequently initiated at least one-dose more frequently (*n*= *130,* 43.9%). Gorbach et al. (2017), also noted over one-fourth (*n*= 217, 26.9%)

of their study participants cited lack of provider recommendation as a barrier to vaccination, however the sample was predominantly cisgender male with only (*n*= 39, 4.8%) identifying as transgender women. Apaydin et al. (2018) also found that SGM people cited negative interactions with primary care providers (PCPs) when discussing their care, especially sexual behavior, as a provider-level barrier to vaccination.

System-level. Singh et al. (2019) identified a lag in HPV vaccination among cisgender women may be associated with the fact that their study was conducted within a few years of the CDC ACIP change in recommendation to include men, women and transgender persons. Apaydin et al. (2018) cited a system-level bias in historical trends in HPV vaccine marketing that targets cisgender straight women whereas transgender women expressed such marketing made them question whether they needed the vaccine or if it would be effective on them. Gorbach et al. (2017) noted the system-level barriers of cost of vaccine and whether insurance would cover the vaccine. Although Halkitis et al. (2019) explored system-level constructs such as residential neighborhood poverty and HIV prevalence, they did not find any association between these system-level factors as HPV vaccination in the cisgender sexual minority males and transgender individuals in their sample.

Vaccination Facilitators.

Patient-level. Fear of disease, specifically genital warts and HIV-coinfection and health concerns related to being HIV-positive, were a motivator for cisgender gay men to receive HPV vaccination in the qualitative study by Aapaydin et al. (2018) In their related study they also observed that participants had over two and half times the odds (OR=2.59; CI 95%, 1.2 - 5.59) of having received HPV vaccination if they had received Hepatitis A/B vaccination and had 1.2 times the odds (OR=1.22; 95% CI, 1.03 - 1.43) of receiving HPV vaccination if they had

received STI screening, however transgender status was not significantly associated with 3-dose vaccine completion.

Provider-level. The single most important provider-level facilitator for HPV vaccination was health care provider recommendation. Gorbach et al. (2017) found that in a predominantly cisgender male sample, individuals who received a provider recommendation for HPV vaccination had nearly twelve times increased odds (aOR=11.85; 95% 6.70-20.98) of vaccinating. Bednarczyk et al. (2017) also noted the profound effect of provider recommendation on vaccination in gender minority participants; nearly all of the transmen who received a recommendation (*n*= 17, 47.2%) also received at least one dose of HPV vaccine (*n*= 14, 41.2%), all of the transwomen (*n*= 1, 6.7%) also received at least one dose of HPV vaccine. Nearly all (*n*= 6, 42.9%) of the non-binary identified participants who received a recommendation also received at least one dose of HPV vaccine (*n*= 7, 50%). Apaydin et al. (2018) found that transgender men expressed that the gender-affirming care they received resulted in comfort levels and trust in their primary care provider which facilitated their receiving a full 3-dose adult vaccine series.

System-level. The most prominent system-level facilitator of vaccination was access to SGM-affirming care and engagement with primary care. Apaydin et al. (2018) found that the percentage of completed primary care appointments among SGM participants was associated with increased odds (OR=1.03, 95% CI 1.01 – 1.05, p = .018) of 3-dose HPV vaccination completion. This study also noted that for all SGM focus group participants regardless of HIV status, gender identity, and/or sexual orientation, having access to an SGM identity-affirming healthcare system was a major facilitator for vaccination. Singh et al. (2019) highlighted that the latest CDC ACIP recommended groups for HPV vaccination do include transgender people and

MSM which would in theory be a policy system-level facilitator. However, the authors point out the HPV vaccination recommendations have not led to significant vaccine uptake in MSM.

Discussion

Synthesis of Findings

This integrative review summarizes existing evidence that explores barriers to and facilitators for HPV vaccination in gender minority people. We identified seven studies that included gender minority people. However, studies rarely treated gender minority participants separately from sexual minority participants when reporting results. This limited our ability to distinguish barriers and facilitators that could be considered specific to gender minority people. Vaccination barriers and facilitators according to the levels of the social ecological model were also explored variably. The studies in our review focused primarily on patient-level and provider-level factors with less attention to system-level factors. The small number of studies that included gender minority people and relatively small proportions of gender minority participants recruited for each study suggests a gap in the literature regarding HPV vaccination among gender minority people. This dearth of knowledge is concerning as evidence suggests that gender minority people have increased risk for HPV infection and HPV-associated cancer than cisgender people (Gatos, 2018; Kobayashi et al., 2017; Peitzmeier, Khullar, et al., 2014; Singh et al., 2019).

Many of the findings for vaccination barriers and facilitators in this review are not unique to gender minority people. For example, facilitators like vaccine knowledge and perceived threat of disease are all also known to be key facilitators for preventive vaccination in the general population (Nowak et al., 2015). However, some facilitators and barriers may be more relevant

and impactful in the context of the gender minority experience. We offer discussion of some of these results through this lens.

The **patient-level** finding that lack of HPV knowledge is a profound barrier to vaccination, especially for gender minority people who are not aware of their risk for HPV disease and may additional misconceptions about HPV vaccination appropriateness related to gender affirmation surgery. These findings support the notion that gender minority people may complex health information needs related to their gender identity (Horvath et al., 2012; MacCarthy et al., 2015). Moreover, anxiety expressed by a transgender participant regarding the need to attend multiple visits for HPV shots may suggest a proxy for anxiety related to engaging with the health care system. This would be consistent with studies that show that gender minority people are more likely to delay care or not receive care due to fear of discrimination and stigma (Bradford et al., 2013; Jaffee et al., 2016)

The **provider-level** finding that provider recommendation is a key facilitator of vaccination is consistent with studies that examined provider recommendation in preventive vaccination in sexual minority communities that is likely also applicable to gender minority communities. A study of MSM found that participants who had received a provider recommendation had over 42 times the odds (OR = 42.23; 95% CI, 14.90 - 19.68) of HPV vaccination initiation than those who did not receive a recommendation (Gerend, Madkins, Phillips, & Mustanski, 2016). The findings from our review reinforce the profound ability of providers to increase HPV vaccination. However, providers who are not culturally competent with respect to gender minority people and their bodies may not recommend HPV vaccination appropriately. Studies have shown that when health care providers lack competence in SGM care, this is a barrier to vaccination (Blackwell, 2016; Wheldon, Sutton, et al., 2018).

Of the **system-level** findings, vaccine cost/insurance coverage is consistent with previous research on cost as a barrier to care among SGM populations (Dahlhamer et al., 2016). Access to care is a well understood facilitator of healthcare and in the case of gender minority communities, access to care from transgender health competent providers is a potential facilitator for preventive care like HPV vaccination (Apaydin, Fontenot, Shtasel, et al., 2018). Research has shown that gender minority people and cisgender sexual minority people who are less 'out' to their medical providers and others in general are also less likely to engage in primary care services like preventive vaccination (Whitehead et al., 2016).

From a policy perspective, national recommendations are another system-level barrier to vaccination for gender minority people. Prior to 2016, MSM were the only SGM group that was mentioned in adult vaccination recommendations, yet gender minority people shared risk factors with MSM especially those relating to sexual health (Castillo et al., 2015). Transgender people were added to the CDC ACIP updated recommendation in December, 2016 (Meites, 2016). Even after the addition of MSM to the vaccine guidelines for HPV, the rates of vaccination in this group continue to lag the general population and there is emerging evidence that gender minority people will also continue to lag the general population despite being added to the national recommendation (Oliver, 2017). Moreover, many national health surveys omit gender identity in their data collection and this limits the ability to describe vaccination trends and determine whether disparities exist for gender minority people.

When considered in gestalt, the findings of this review begin to outline an integrated perspective of HPV vaccination in gender minority people that emphasizes a set of key facilitators including patient knowledge of HPV risk, compelling recommendations from health

care providers who are attuned to their needs and national vaccination recommendations that establish gender minority people as a priority at-risk population to offer vaccination.

Limitations

This review addresses a gap in the literature regarding barriers to and facilitators for HPV vaccination in gender minority people but is not without several limitations. First, although we conducted a thorough search of the literature from three major databases, it is possible that we missed studies that were indexed in other databases. We did not include grey literature in our search which may have further excluded relevant citations, especially non-quantitative studies. We restricted our inclusion criteria to U.S.-based studies only which may have excluded studies that had larger proportions of gender minority people or studies focused solely on this group. Because of the limited number of studies that included gender minority people in the sample, this necessitated considering study results that mixed SGM people together. Although SGM people may experience similar challenges relating to dear of discrimination and stigma in healthcare, there is growing evidence that gender minority people have unique healthcare needs and may engage in preventive care differently than cisgender sexual minority people (Edmiston et al., 2016).

Conclusion

This study identifies the current evidence that describes barriers to and facilitators for HPV vaccination in gender minority people. Few studies were identified that included gender minority people and the low proportion of gender minority participants in each study sample points to a significant gap in knowledge about this population that warrants further research. Our review highlights some of the factors that contribute to disparities HPV vaccination among SGM people overall and that gender minority people may have additional patient-level, provider-level

and system-level factors that influence HPV vaccine uptake. Future avenues for research should focus on recruiting gender minority people to better explore HPV vaccination from their perspectives.

Table 2. 1 Studies included in the literature review with summary features

Author (Year)	Study design	Select sample characteristics	Barriers	Facilitators	Quality Criteria
Apaydin *et al.* (2018)a	Cross-sectional EHR data *N*= 301 Clinic, Boston, MA	Trans men/women Genderqueer Cis male/female Lesbian, Gay, Bisexual, Heterosexual Age (*M* = 26.3, *SD* = 2.48)	Patient: documented substance use disorder, education attainment lower than some college / post-secondary school	Patient: education attainment 4-college or higher, attended primary care visits, received vaccination for hepatitis A/B, received screening for STIs	6/8
Apaydin *et al.* (2018)b	Qualitative Descriptive Focus Group *N* = 15 Boston, MA	Trans men/women Cis male/female Lesbian, Gay, Bisexual, Heterosexual, Asexual, Pansexual Age (*M* = 25, *SD* = 1)	Patient: lack of awareness of HPV/vaccine, misconception that vaccine is gender-specific Provider: lack of awareness about HPV and relevance to SGM; lack of SGM care competency System: 3-dose vaccine schedule	Patient: proactive health-seeking behaviors, fear of genital warts, fear of health problems after HIV seroconversion, pre-existing health conditions that promote engagement System: access to health care affirming to sexual identity	No major concerns Not discussed: theoretical model, audit trails, member checks

Author (Year)	Study design	Select sample characteristics	Barriers	Facilitators	Quality Criteria
Bednarczyk *et al.* (2017)	Cross-sectional Online survey *N* = 660 Rural ZIP codes	Trans men/women Non-binary Cis male/female Age (range 18 to 34)	Patient: lack of provider recommendation Provider: bias against vaccinating male sex assigned at birth,	Patient: provider recommendation Provider: bias towards vaccinating female sex assigned at birth	7/8
Fontenot *et al.* (2016)	Cross-sectional EHR data *N* = 2,537 Clinic, Boston, MA	Trans men/women Cis male/female Lesbian, Gay, Bisexual, Queer, Heterosexual Age (*M* = 21-22, *SD* = 3)	Patient: transgender identity	Patient: having private insurance, annual examination, received another non-HPV vaccine, received cervical Pap test, received STI test, engaged in oral sex	6/8

Author (Year)	Study design	Select sample characteristics	Barriers	Facilitators	Quality Criteria
Gorbach *et al.* (2017)	Cross-sectional In-person computer assisted interview *N* = 1,033 Los Angeles, CA & Chicago, IL	Trans women Cis male Sexual Orientation: Gay, Bisexual, Queer Age (*M* = 23, *SD* = 2)	Patient: not knowing where to get vaccinated, safety concerns Provider: Lack of recommendation System: cost, insurance not covering vaccine	Patient: appointment in past year, disclosed sexual orientation, screened for HIV/STIs, received other vaccines (Hepatitis A/B) Provider: recommendation System: private clinic rather than LGBT or public clinic	8/8
Halkitis *et al.* (2019)	Cohort *N* = 486 New York, NY	Trans men Cis male Age (*M* = 23.7, *SD* = 0.7)	System: no significant difference in HPV vaccination by neighborhood poverty or HIV prevalence, age, education, sexual orientation, gender identity, or income	None identified	8/8

Author (Year)	Study design	Select sample characteristics	Barriers	Facilitators	Quality Criteria
Singh *et al.* (2019)	Cross-sectional In-person computer assisted interview *N* = 1,033 Los Angeles, CA Chicago, IL	Gender: Transgender women Cisgender male Sexual Orientation: Gay/homosexual Bisexual Heterosexual/straight Other/unknown Age (range 18 to 26)	Patient: Lack of knowledge of HPV risk, HPV vaccine, unsure whether could obtain HPV vaccine if wanted, lower education attainment	System: CDC ACIP HPV vaccine recommendations include transgender persons as of 2016	8/8

Table 2. 2 Methodological appraisal of cross-sectional studies

Cross-sectional study JBI quality criteria	Apaydin (2018)	Bednarczyk (2017)	Fontenot (2016)	Gorbach (2017)	Halkitis (2019)	Singh (2019)
1. Criteria for inclusion in the sample clearly defined?	Y	Y	Y	Y	Y	Y
2. Study subjects and the setting described in detail?	Y	Y	Y	Y	Y	Y
3. Exposure measured in a valid and reliable way?	Y	Y	Y	Y	Y	Y
4. Objective/standard criteria used for measurement?	Y	Y	Y	Y	Y	Y
5. Confounding factors identified?	N	Y	N	Y	Y	Y
6. Strategies to deal with confounding factors stated?	N	N	N	Y	Y	Y
7. Outcomes measured in a valid and reliable way?	Y	Y	Y	Y	Y	Y
8. Appropriate statistical analysis used?	Y	Y	Y	Y	Y	Y
Score	6	7	6	8	8	8

Y=yes, N=no

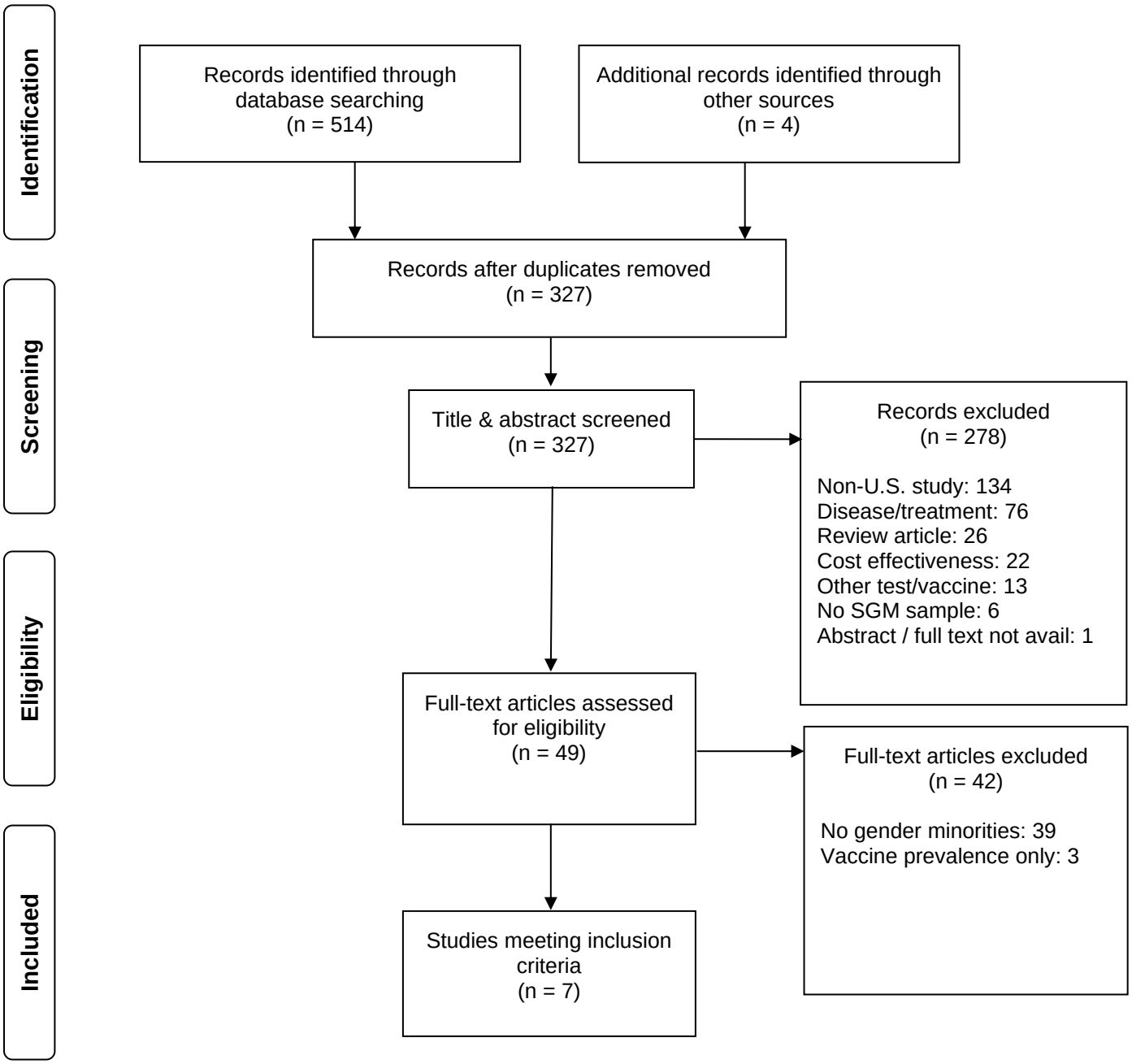

Figure 2. 1 *PRISMA* Flow Diagram for Literature Search

Chapter 3: The PRIDE Study Dataset

Dataset Selection

The PRIDE Study (The PRIDE Study, 2019), is a large-scale, longitudinal, U.S.-based, national, cohort study of adult sexual and gender minority (SGM) people that includes lesbian, gay, bisexual, transgender, gender expansive, and queer (LGBTQ) identified people. The overarching goal of the study is to improve the health of LGBTQ people and better understand how does being LGBTQ influence physical, mental or social health over time. The PRIDE Study is participant- and community-centric, engaging SGM communities who are involved in health advocacy and research through its national network called PRIDEnet. As of June 2020, PRIDEnet includes a 32-member Community Partner Consortium composed of health clinics that serve SGM communities, community centers and professional/advocacy organizations for SGM people; an 11-member Participant Advisory Committee composed of members from the SGM community to provide study oversight and guidance, and eight PRIDEnet ambassadors who facilitate communication and representation of SGM communities nation-wide.

The PRIDE Study recruits participants through PRIDEnet partners using multiple strategies including snowball, word-of-mouth, and Internet social media campaigns. The study has enrolled more than 18,800 people since launching in May 2017. As of April 2019, over one-third (32.8%) of the cohort identified as a gender minority and nearly all (98.7%) identified as a sexual minority. In terms of sexual orientation, over one-third of the sample identified as queer (35.7%) or gay (34.4%) and just under one-third identified as bisexual (27.5%). The cohort was majority (91.7%) white race. The next largest racial / ethnic group represented in the cohort include includes individuals of Hispanic/Latino/Spanish ancestry (8.4%), followed by Asian (4.3%), African-American (4.1%), and American-Indian/Alaska Native individuals (3.5%). Most

of the cohort (91.3%) reported having some college of more educational attainment. Considering the disproportionate representation of white and college-educated participants, The PRIDE Study is not necessarily representative of the SGM people in the U.S. However, participants reside in all major census regions (Lunn, Lubensky, et al., 2019).

The PRIDE Study maintains an online Web portal for participants at pridestudy.org. The portal provides a site for online enrollment and hosting online survey questionnaires. The PRIDE Study collects data via both its online novel Web portal platform and Qualtrics. The PRIDE Study Annual Questionnaire (AQ) is an online survey and is meant to capture a comprehensive view of a participant's physical, mental, and social health. The AQ is launched every June and typically takes 45-75 minutes to complete. The survey is organized into five blocks (Introduction, Mental Health, Physical Health, Social Health, and Miscellaneous). The AQ also collects information about past medical history, past surgical history, receipt of vaccines, and receipt of other preventative care such as cancer screening. The AQ captures information about social history, substance use, sexual behavior and satisfaction, and behavioral health. Finally, the AQ includes items relating to SGM identity, including experiences of stigma and discrimination, identity formation, acceptance from self and others like health care providers about SGM status, social supports, family formation and structure and others. (Lunn, Capriotti, et al., 2019; Lunn, Lubensky, et al., 2019; The PRIDE Study, 2019). In addition to the yearly follow-up AQ, The PRIDE Study hosts additional questionnaires throughout the year for topics that are not covered in the AQ. For example, in March 2020, the study launched a survey related to the effects of Coronavirus Disease 2019, or COVID-19 on the health and well-being of SGM people.

We established an ancillary study agreement with The PRIDE Study (The PRIDE Study, 2019) to obtain data for this dissertation using both existing survey items and adding new survey

items. Approval for our ancillary study was obtained by two rigorous study applications and research proposal reviews by The PRIDE Study Research Advisory Committee and Participant Advisory Committee. We performed a detailed review of the codebook of the dataset to determine available items and potential gaps. Through a collaborative process it was determined that responses from The PRIDE Study Annual Questionnaire 2018-19 would be used for Study Aim Two because this version of the survey included key outcome variables: receipt of HPV-vaccine (ever) and number of HPV-doses received.

Use of The PRIDE Study cohort data set overcomes limitations of previous studies to explore factors associated with HPV vaccination among TGNB people. Previous studies using large samples of TGNB people have emphasized describing TGNB population demographics, and those that have examined preventive behaviors have not described HPV vaccination (Crissman et al., 2017; Herman et al., 2017; Meyer et al., 2017). TGNB people have been included in studies that focus on sexual health but not as the primary population of interest, frequently representing <10% of study sample (Cao et al., 2017; Choi et al., 2017). This has limited the generalizability of previous studies. The PRIDE Study cohort is a national convenience sample of SGM that includes diverse identity information, including less commonly described sexual orientations such as queer (i.e. other than bisexual, gay, heterosexual, lesbian) and less commonly described gender identities such as genderqueer (i.e. other than man, transgender man, transgender woman, woman) which enables more accurate categorization of individuals and more meaningful comparisons for this dissertation.

The PRIDE Study collects patient-reported data including individual health behavior related to sexual identity such as non-disclosure of sexual identity to healthcare providers. Consequently, the use of this rich dataset enables the investigation of potential factors related to

vaccination that are specific to TGNB people such as whether individuals delayed or did not receive care due to concern that they would be discriminated against because of their gender identity.

Identification of Additional Survey Items.

We operationalized an adapted version of the Integrative Model for eHealth Use as part of our comprehensive review of The PRIDE Study codebook and identified gaps in the following three areas: 1) health information-seeking behavior, 2) general health literacy, and 3) eHealth literacy. These constructs are explored in Study Aim Three. We were informed by our sponsor's previous research regarding health information-seeking and general health literacy that adapted items from the national Health Information National Trends Survey also knowns as HINTS (National Cancer Institute, 2018), and used general health literacy items proposed by Chew et al. (2004). Health information seeking items were informed by a previous study of online health information-seeking behavior as part of the Washington Heights Inwood Informatics Infrastructure for Comparative Effectiveness Research (WICER) Study (Lee et al., 2014). We propose to use a more extensive set of the HINTS items in our study that was informed by previous studies of health information seeking among sexual minority people (Jabson et al., 2017; Langston et al., 2019; Lee et al., 2017). Online health information seeking can be assessed by various means, but the straight-forward approach used by HINTS is simply to ask if an individual goes online to seek information about a specific health issue such as HPV vaccination (Anker et al., 2011).

To determine how to measure eHealth literacy, we also undertook a detailed item review of the only validated electronic health literacy measure available to-date, the eHealth Literacy Scale also known as eHEALS (Appendix B), which has been used in numerous settings and

populations including sexual minority people such as MSM (Horvath & Bauermeister, 2017; Norman & Skinner, 2006). To ensure completeness of data collection, the items used for primary data collection (Study Aim Three) included existing PRIDE Study survey items that reflect our adapted Integrated Model of eHealth Use.

The remaining constructs in the new survey include health knowledge/beliefs, situation, Internet use, and demographics. Although The PRIDE Study annual survey includes items that represent these constructs, we did not rely on previous Annual Questionnaire survey responses for the new survey. To ensure completeness of prospectively collected data, the new survey included novel items (*i.e.*, health information seeking, general and eHealth literacy), as well as items of interest that previously appear in The PRIDE Study AQ (*e.g.*, health knowledge/beliefs, situation, Internet use, and demographics). The variables proposed for the new primary data collection survey (Study Aim Three) are described in Chapter 5.

Comparison Groups

The PRIDE Study collects gender identity information in the two-step manner recommended by Office of the National Coordinator for Health Information Technology, including sex assigned at birth and gender identity (Cahill et al., 2016; Deutsch et al., 2013). The dataset also includes information on lived gender. Having responses to these three gender identity items was critical to the formation of our comparison groups. The primary comparison groups for Study Aim Two and Study Aim Three are described in Table 3.1. We include the Boolean logic and variables used for each group.

Our prospective survey is assembled from valid and reliable instruments (Appendix B,C,D,E). The health information seeking items are drawn from HINTS 5 Cycle 3 (National Cancer Institute, 2018) and the electronic health literacy from the latest version of the eHEALS

scale (Norman & Skinner, 2006) that has been validated for use in multiple languages and settings (Aponte & Nokes, 2017; Chung & Nahm, 2015). The three discrete subjective general health literacy items have also been validated as an alternative to longer format health literacy instruments (Chew et al., 2004). Finally, we leverage the existing PRIDE Study AQ items to assess demographics, barriers to care, access to care and preventive care that have undergone rigorous review and revision by The PRIDE Study/PRIDEnet Participant Advisory Committee and Research Advisory Committee year over year since the launch of the study in 2017. Our secondary analysis leverages existing survey items in the AQ 2018-19 to provide the necessary data to achieve our study aims.

Table 3. 1 Comparison groups

Comparison	Group	Reference
A1. TGNB all compared to: Cisgender all	TGNB (ALL) Administrative identification / stratified by gender identity (A2 ALL and A3 ALL)	CISGENDER (ALL) Administrative identification / stratified by gender identity (A2 ALL and A3 ALL)
A2. Transgender men compared to: Transgender women	Transgender Man SAAB (Female2) AND GENDERID (Genderqueer1 OR Transgender man3 OR Man2 OR Another gender identity6)	Transgender Woman SAAB (Male1) AND GENDERID (Genderqueer1 OR Transgender woman4 OR Woman5 OR Another gender identity6)
A3. Cisgender female compared to: Cisgender male	Cisgender Female SAAB (Female2) AND GENDERID (Woman5)	Cisgender Male SAAB (Male1) AND GENDERID (Man2)
B1. TGNB organs born female compared to: Cisgender female	GENDERID (Genderqueer1 OR Transgender man3 OR Transgender woman4 OR Man2 OR Another gender identity6) AND ORGANS_BORN (cervix1 OR ovaries2 OR uterus OR vagina7)	GENDERID (Woman5) AND ORGANS_BORN (cervix1 OR ovaries2 OR uterus6 OR vagina7)
B2. TGNB organs born male compared to: Cisgender male	GENDERID (Genderqueer1 OR Transgender man3 OR Transgender woman4 OR Woman5 OR Another gender identity6) AND ORGANS_BORN (penis3 OR prostate4 OR testicles5)	GENDERID (Man2) AND ORGANS_BORN (penis3 OR prostate4 OR testicles5)
C1. Organs born male + organs now female compared to: Organs born male + organs now male	ORGANS_BORN (penis3 OR prostate4 OR testicles5) AND ORGANS_NOW (vagina8)	ORGANS_BORN (cervix1 OR ovaries2 OR uterus6 OR vagina7) AND ORGANS_NOW (cervix2 OR ovaries3 OR uterus7, vagina8)
C2. Organs born female + organs now male compared to: Organs born male + organs now male	ORGANS_BORN (cervix1 OR ovaries2 OR uterus6 OR vagina7) AND ORGANS_NOW (penis4 OR testicles6)	ORGANS_BORN (penis3 OR prostate4 OR testicles5) AND ORGANS_NOW (penis4 OR prostate5 OR testicles6)
D1. TGNB + Organs Now Female + AFAB compared to: Cisgender + Organs now female +AFAB	GENDERID (Genderqueer1 OR Transgender Man3 OR Transgender Woman4 OR Another gender identity6) AND ORGANS_NOW (cervix2 OR ovaries3 OR uterus7 OR vagina8) AND SAAB (Female2)	GENDERID (Woman5) AND ORGANSNOW (cervix2 OR ovaries3 OR uterus7 OR vagina8) AND SAAB (Female2)

Comparison	Group	Reference
D2. TGNB + Organs Now + Assigned Male at Birth (AMAB) compared to:	GENDERID (Genderqueer1 OR Transgender Man3 OR Transgender Woman4 OR Another gender identity6) AND ORGANS_NOW (vagina8) AND SAAB (Male1)	GENDERID (Man2) AND ORGANS_NOW (penis4 OR prostate5 OR testicles6) AND SAAB (Male1)
E1. Binary Identity Transmasculine ALL compared to: Transfeminine ALL	GENDERID (Genderqueer1 OR Transgender Man3 OR Another gender identity6) AND LIVEGEN (Man1) OR GENDERID (Man3) AND SAAB (Female2) AND LIVEGEN (Man1)	GENDERID (Genderqueer1 OR Transgender Man3 OR Another Gender Identity6) AND LIVEGEN (Woman2) OR GENDERID (Woman5) AND SAAB (Male1) AND LIVEGEN (Woman2)
F1. Nonbinary Identity Nonbinary + AFAB compared to: Nonbinary + AMAB	GENDERID (Genderqueer1 OR Another Gender Identity6) OR LIVEGEN (Sometimes man / sometimes woman3 OR Third gender other than man or woman4) AND SAAB (Female2)	GENDERID (Genderqueer1 OR Another Gender Identity6) OR LIVEGEN (Sometimes man / sometimes woman3 OR Third gender other than man or woman4) AND SAAB (Male1)
F2. Transgender Nonbinary ALL compared to: Transgender Binary ALL	(F1 ALL)	(E1 ALL)

AFAB (Assigned Female at Birth)
AMAB (Assigned Male at Birth)
SAAB (Sex Assigned at Birth)
TGNB (Transgender and Gender Nonbinary)

Chapter 4: Human papillomavirus vaccination among transgender and gender nonbinary people: a cross-sectional secondary analysis of The PRIDE Study 2018-19 annual questionnaire

The study in Chapter Four addresses the second aim of the dissertation to compare rates of HPV vaccination initiation and completion among TGNB and cisgender sexual minority people, compare HPV knowledge, situation factors (*e.g.,* barriers to care, access to care, preventive care), Internet use, and HPV risk activities among these groups. The study is a cross-sectional secondary analysis of responses from participants in The PRIDE Study Annual Questionnaire 2018-19.

Background

Human papillomavirus (HPV) is the most common sexually-transmitted infection (STI) in adults in the United States with a prevalence of 79 million existing infections and incidence rate of 14 million new infections per year (Dunne et al., 2014). High-risk strains of HPV are associated with the majority of recto-anal, vagino-cervical, and oropharyngeal cancers (Centers for Disease Control and Prevention, 2013; Dunne et al., 2014). A vaccine to prevent HPV-infection was introduced in 2006. The Advisory Committee on Immunization Practices (ACIP) recommends two doses of vaccine starting at age 9-11 years and three adult "catch-up" doses for those who have not had received any vaccine doses by age 15-years. The national goal proposed in Healthy People 2020 was 80% vaccine completion for HPV (*e.g.*, received the full vaccination series, or all recommended doses based on age group) (Markowitz et al., 2014). The Centers for Disease Control and Prevention (CDC) estimates that approximately fifty-four percent of eligible adolescents have achieved vaccine completion and approximately 23 million young adults

remain unvaccinated for HPV in the general population (Elam-Evans et al., 2020; Walker et al., 2017; Williams et al., 2017). In June 2019, ACIP expanded the recommended age range from 9 through 26 years to 9 through 45 years for both women and men (Meites, 2019).

Low HPV vaccine completion (13 to 32%) has been observed in adult sexual minority populations defined by their sexual orientation *i.e.*, gay men, lesbian women, bisexual men and women (Agenor, Peitzmeier, et al., 2016; McRee et al., 2014; Reiter et al., 2015; Williams et al., 2017). Studies have identified lack of knowledge or trust in vaccines, non-disclosure of sexual identity to providers, and fear of discrimination/stigma as barriers to vaccination in sexual minority people (Barefoot et al., 2017; Cummings et al., 2015; Gerend, Madkins, Phillips, Mustanski, et al., 2016; McRee et al., 2014; Youatt, 2017). Less is known about HPV vaccination among gender minorities known as transgender and gender nonbinary (TGNB) people, who are estimated to number at least 1.4 million in the U.S. (Flores, 2016). Unlike cisgender sexual minority people whose gender identity matches their assigned sex at birth, TGNB people have gender identities/expressions that may not conform to their assigned sex at birth and may self-identify as transmen/women, transgender men/women or men/women (American Psychological Association, 2015; Institute of Medicine, 2011). Some TGNB people self-identify as nonbinary or genderqueer, terms used to describe people whose gender is not exclusively male or female, including those who identify with a gender other than male or female, as more than one gender, or as no gender (James, 2016). For the purposes of this study, we use the terms transgender and gender nonbinary (TGNB) to encompass these communities, however we acknowledge that TGNB may not capture all that ways in which gender minority people express their identities. Sexual and Gender Minorities (SGM) were designated a Health Disparities Population (HDP) for research purposes by the National Institutes of Health (NIH) in

recognition of the health disparities and unique health challenges that face these communities (Pérez-Stable, 2016).

Problem Statement

The true proportion of adult TGNB and cisgender sexual minority people who have not received any doses of HPV vaccine is likely higher than the general population given studies to-date (Agenor, McCauley, et al., 2016; Agenor et al., 2015; Agenor, Peitzmeier, et al., 2016; Charlton et al., 2017; McRee et al., 2014; Reiter et al., 2015). TGNB people report a higher prevalence of poor health and experience stigma and discrimination with healthcare providers based on their gender identity, resulting in poor health outcomes from delaying or deferring necessary care (Bradford et al., 2013; Jaffee et al., 2016; Macapagal et al., 2016; Meyer et al., 2017; Safer et al., 2016; Winter et al., 2016). For example, TGNB people with a cervix who are sexually active are at risk of HPV and yet have reduced rates of cervical cancer screening and increased time between recommended screening intervals compared to cisgender women (Peitzmeier, Khullar, et al., 2014; Peitzmeier, Reisner, et al., 2014). There have been few studies that focus on receipt of HPV vaccination among TGNB people. A small study of rural-residing TGNB people noted variation in HPV vaccination initiation (*e.g.*, received at least one HPV shot); the greatest proportion who initiated were nonbinary people assigned female at birth (n = 18, 62.1%), followed by transmen (n = 15, 36.6%), nonbinary people assigned male at birth (n = 1, 20%), and the smallest proportion initiating vaccination transwomen (n = 1, 5.3%) (Bednarczyk et al., 2017). Although this research also noted a significant association between healthcare provider recommendation and receipt of a HPV vaccine shot, the study's small sample limits its generalizability (Bednarczyk et al., 2017). Studies among cisgender sexual minority people have similarly shown a positive association between provider recommendation and HPV

vaccination (Gerend, Madkins, Phillips, Mustanski, et al., 2016; Gorbach et al., 2017; McRee et al., 2014).

SGM people have demonstrated increased risk of HPV infection and HPV-related cancers. Although HPV is thought to be a highly prevalent in the general population, studies have shown increased risk of HPV infection among SGM people including increased rates of oropharyngeal, cervical, and anal HPV infection (D'Souza et al., 2017; Forner et al., 2018; Machalek et al., 2012; Singh et al., 2019). A recent study found that the prevalence (PR 1.3; CI 95%, 1.1 – 1.4) of anal HPV infection was 1.3 times greater for transgender women than cisgender men who have sex with men, or MSM (Singh et al., 2019). Higher rates of HIV-infection have been observed among TGNB people compared to the general population which is thought to increase their risk of HPV-associated cancer (Poteat et al., 2016; Quinn et al., 2015).

Cisgender sexual minority people and TGNB people may experience unique barriers to vaccination. Studies to date that explore HPV vaccination barriers have focused mostly on cisgender minority individuals. Yet, TGNB people often experience similar barriers to healthcare as cisgender sexual minority people (Cruz, 2014; Edmiston et al., 2016). All SGM people may experience increased fear of discrimination and stigma from healthcare providers, and these pose a barrier to obtaining HPV vaccination (Barefoot et al., 2017; Cummings et al., 2015; Meyer, 2003). Similarly, individuals who fear discrimination may not disclose their sexual identity to healthcare providers, which has also been observed to be a significant barrier to preventive vaccination (Gerend, Madkins, Phillips, Mustanski, et al., 2016; Wheldon et al., 2017; Youatt et al., 2017). Lack of HPV and vaccine knowledge is a known barrier to vaccination, and studies have shown that TGNB people and cisgender MSM may be unaware that HPV vaccination is

recommended for both men and women (Apaydin, Fontenot, Shtasel, et al., 2018; Wheldon et al., 2017).

HPV vaccination is effective when the recommended 3-dose vaccine series is completed; however, studies have not always assessed number of doses. The vaccine has been shown to be highly effective, with one analysis of a national probability sample demonstrating a 61% reduction in prevalence in HPV infection in adult females age 20-24 years within eight years of vaccine introduction (Oliver et al., 2017). Another analysis projects a 90% reduction of HPV-related cancers through vaccination (Saraiya et al., 2015). Although there is emerging evidence that even one-dose of HPV vaccine may be beneficial (Sonawane et al., 2019), previous studies have shown that adults who receive only one-dose of the vaccine are not completely protected from HPV infection, whereas three-doses provides immunity and more adequately prevents HPV-related cancers (Kang et al., 2018). Studying vaccination initiation versus completion is important for understanding HPV risk, yet previous studies often neglected report number of doses, representing a critical gap in knowledge (Fuller & Hinyard, 2017; Oliver, 2017).

Methods

The Integrative Model of eHealth Use or IMeHU (Bodie & Dutta, 2008) guided our study. The model posits that online health information seeking is associated with health behavior outcomes and that this relationship is influenced by situational factors like barriers to care, access to care, preventive care and Internet use (Figure 4.1). We explore the role of online health information seeking and the role of moderators like eHealth literacy and general literacy on the receipt of HPV vaccine in a separate study (Chapter 5). For the current study, we focus on describing individual situational factors (other than health information seeking) that may

influence the receipt of HPV vaccination. We compare HPV risk among TGNB people and cisgender sexual minority people.

To achieve our study aims, we performed a secondary cross-sectional analysis of participants in The Population Research in Identities and Disparities for Equality (PRIDE) Study (pridestudy.org), a large-scale long-term U.S.-based national health study of SGM people (The PRIDE Study, 2019). The PRIDE Study launched in 2017 and recruits only adults age 18-years and older. The current cohort is estimated to be more than 18,800 participants. The PRIDE Study launches an Annual Questionnaire (AQ) to its participants in the months of May or June. For the purposes of our cross-sectional analysis, we used the follow-up period from May 2018 to May 2019 as it included questions about receipt of HPV vaccine, number of doses, and HPV knowledge. Additional details of The PRIDE Study longitudinal cohort and dataset are described elsewhere (Lunn, Capriotti, et al., 2019; Lunn, Lubensky, et al., 2019). This study was approved by the Institutional Review Boards at Columbia Irving University Medical Center (IRB-AAAS6719) and Stanford University Medical School.

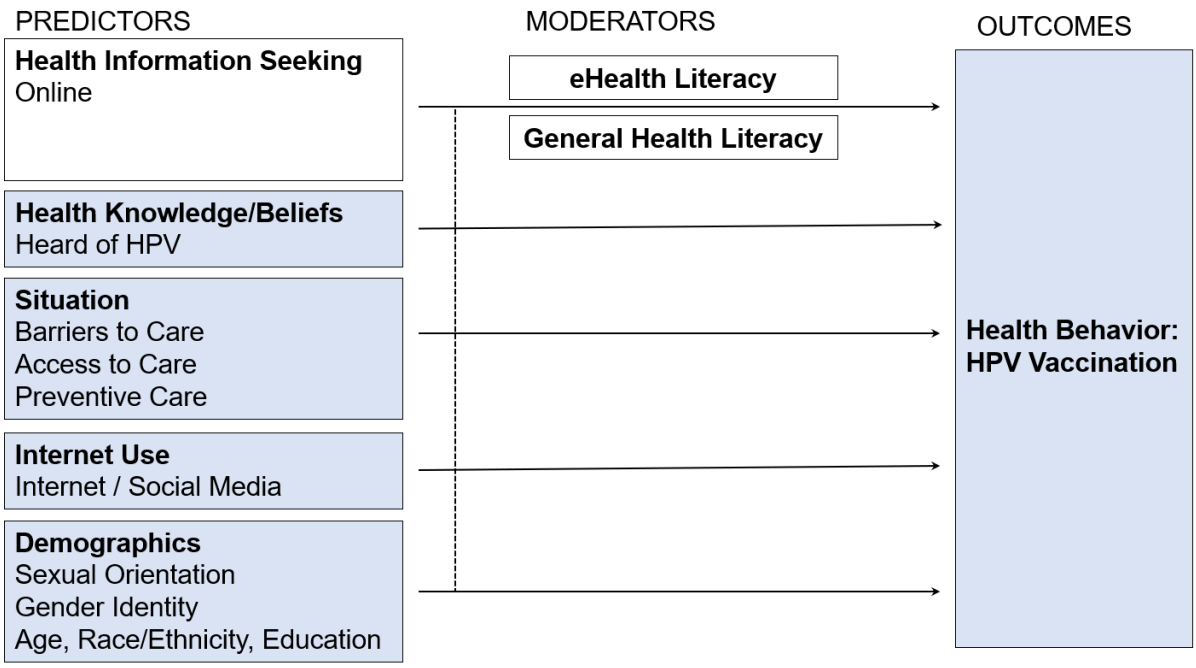

Figure 4. 1 Adapted Integrative Model of eHealth Use (IMeHU)
[Shaded areas denote areas of focus in this study]

All participants in The PRIDE Study cohort 2018-19 were deemed eligible for the online survey with no age restrictions and no restrictions to participant sexual or gender identity demographic information. The PRIDE Study collects participant survey data online using Qualtrics (Qualtrics, Provo, UT). Participants can skip any item and start and stop the survey as much as they like during survey periods by logging into their existing PRIDE Study Web portal accounts.

We conducted review of the 2018-19 Annual Questionnaire codebook to determine variables to include in the analysis using the IMeHU *a priori* to categorize situational factors. The survey item categories and number of items in each category were distributed as follows: HPV and vaccine knowledge (3-items), barriers to care (12-items), access to care (6-items), preventive care (10-items), and demographic (16-items), Internet-use (2-items), HPV Risk (9-

items). Survey responses from TGNB participants were compared with cisgender sexual minority participants as the reference group.

Comparison Groups

We used the responses from multiple demographic questions (*e.g.*, gender identity, lived gender day-to-day, assigned sex at birth, organs born with, organs now) to identify TGNB participants and distinguish them from cisgender participants. We used Boolean logic to account for both gender identity and biological sex. Table 4.1 summarizes the comparison groups and our inclusion logic.

Statistical Analysis

The dataset was cleaned, and all analysis performed in SAS 9.4 (SAS Institute Inc., Cary, NC). Descriptive statistics for demographics were calculated and means and standard deviations established. Chi-square and paired t-tests were employed to examine differences in categorical and continuous variables. The distribution of continuous variables and potential outlier values for age and age at sexual debut were identified using boxplots in SAS. To determine if multicollinearity was present, we used variance inflation factor (VIF) statistics. A VIF value less than five suggested no multicollinearity (Akinwande et al., 2015). We calculated point prevalence for receipt of HPV vaccine (ever), vaccine initiation (*e.g.*, 1-dose) vaccine completion (*e.g.*, 3-doses). We calculated prevalence ratios (PR) and confidence intervals (CI) using robust Poisson statistics (Petersen & Deddens, 2008). The prevalences of receipt of HPV vaccination ever, vaccine initiation and vaccine completion were stratified by gender identity, sex organs born with, sex organs now, and sex assigned at birth. Alpha was set at .001 for level of significance to control for galloping alpha due to the large number of comparisons between groups.

Results

We combined responses from the primary AQ 2018-19 survey that included 7,325 responses and a one-time supplemental survey that captured Internet-use items during the same survey timeframe with 5,619 responses. The combined surveys had 7,535 responses and 5,733 of these completed the entire survey (*e.g.*, viewed every page of the survey). We further excluded 233 (4.1%) of the completed surveys that were missing gender identity, lived gender and/or sex assigned at birth information that were necessary for our comparison groups. The final dataset included 5,500 survey responses.

Of the remaining 5,500 survey responses, a total of 1,691 (31%) were completed by TGNB participants, and 3,859 (69.5%) completed by cisgender sexual minority participants (Table 4.2). A greater proportion of TGNB participants were assigned female at birth (AFAB) (78.2%) compared to cisgender AFAB (58.6%) ($p < .0001$). Conversely, the proportion of TGNB participants who were assigned male at birth (AMAB) (21.8%) participants was about half of cisgender AMAB (41.4%) ($p < .0001$). Greater than one-third (39.8%) of TGNB participants said their lived gender day-to-day was sometimes man/woman or a third gender or something other than a man or woman. Over half (58.1%) of TGNB participants identified as queer sexual orientation compared to one-third (29.1%) of cisgender sexual minority participants ($p < .0001$). The majority of TGNB and participants were white race (80.8%) and had more than a high school education (90.0%), cisgender participants were similarly majority white (82.1%) and a greater proportion had more than a high school education (93.4%) ($p < .0001$). Although majority of both groups reported they worked one or more paid jobs, TGNB participants reported lower annual income than cisgender participants with more than three-quarters (80.9%) of TGNB participants with an income less than $50,000 per year compared to cisgender participants

(61.8%) ($p < .0001$). More cisgender participants rated their health as fair/poor (47.9%) compared to TGNB participants (34.7%) ($p< .0001$). The median age of participants was 31 (interquartile range [IQR], 25-41). Cisgender participants were slightly older than TGNB participants, mean age 36.3 SD 13.9 and mean age 31.3 SD 11.4, respectively ($p < .0001$). Of note, for all demographic variables we report participant responses as discrete categories, multiple responses options were not analyzed.

Barriers to Care

The proportion of TGNB participants who reported ever being denied or given lower quality medical care was two times (30.9%) that of cisgender participants (15.6%) ($p < .0001$). The reasons for being denied or given lower quality care differed between the groups. TGNB people reported race/ethnicity most frequently (16.7%) compared to cisgender participants (3.1%), but cisgender participants most frequently reported gender identity (12.2%) as the reason for being denied or given lower quality care compared to TGNB participants (3.2%) ($p < .0001$).

One-third (31.9%) of TGNB participants reported they delayed necessary medical care in the past year compared to cisgender participants (16.8%) ($p < .0001$). Both groups similarly reported that their insurance company would not cover the care as the most frequently mentioned reason for delaying care, TGNB (14.5%) and cisgender (14.6%), but a greater proportion (12.4%) of cisgender participants reported that they delayed care because they could not afford it compared to TGNB participants (5.5%) ($p = .0003$). The proportion of TGNB participants who reported putting off seeing a health care provider because of concern that they would be disrespected or mistreated in the past year was three-times (34.5%) the proportion of cisgender participants (10.9%) ($p < .0001$). Over half (55.3%) of TGNB participants cited age as the reason they put off seeing a health care provider compared to (7.3%) cisgender participants whereas a

greater proportion (19.7%) of cisgender participants reported gender identity as the reason for putting off seeing a health care provider compared to (3.7%) TGNB participants ($p < .0001$). Lastly, the proportion of TGNB participants who reported they were unable to obtain necessary medical care, tests or treatments in the past year was two-times (21.4%) that of cisgender participants (9.8%) ($p < .0001$). Both groups reported the most frequent reason they were unable to obtain care was their insurance company would not cover their care, (33.4%) TGNB and (36.3%) cisgender ($p = .0009$). The groups were also similar in reporting not being able to afford the care as the second most reported reason for being unable to get medical care, tests, or treatment, (26.8%) TGNB and (27.3%) cisgender ($p = .0009$).

Access to Care

Nearly all participants in both groups reported having a primary care provider (PCP), having seen their PCP in the past year, and nearly all reported having insurance. Majority of both groups reported having private insurance but a greater proportion (14.3%) of TGNB participants had Medicaid or Medicare compared to (10.5%) cisgender ($p < .0001$). Over half (55.8%) of TGNB participants reported having gone to a provider/clinic for transgender care in the past year and over half (56.2%) reported having ever taken hormones for gender affirmation.

Preventive Care

Nearly half (47.9%) of cisgender participants reported their health was fair or poor compared to about one-third (34.7%) of TGNB participants ($p < .0001$). Both cisgender and TGNB participants reported receiving vaccines other than HPV. Hepatitis-B was the most frequently reported vaccine other than HPV and majority of both groups reported receipt of Hepatitis-B vaccine.

Internet Use

A greater proportion (73.3%) of TGNB participants reported using dating apps than (65.9%) cisgender participants ($p < .0001$). The most popular dating apps for both groups were Adam4Adam, Tinder and OK Cupid. Both groups were similar in terms of the time spent on apps, with over half of each group reporting less than one hour spent using the app per week. One-third (32.2%) of cisgender participants reported one to six hours per week compared to one-fourth (24.9%) of TGNB participants ($p < .0001$).

HPV Risk

The median age of sexual debut for all participants was 18 (interquartile range [IQR], 15-25). The mean age of sexual debut did not differ between the groups; mean 17.3 SD 4.8 for TGNB participants and 17.8 SD 5.2 for cisgender participants ($p = .2224$). The median number of lifetime sexual partners for all participants was 6 (interquartile range [IQR], 2-15). Cisgender participants averaged two times the number of lifetime sexual partners mean = 16.1 SD 18.3 compared to TGNB participants mean = 8.6 SD 12.1 ($p < .0001$). Both TGNB participants and cisgender sexual minority participants reported receptive sexual activities that would put them at risk of exposure to HPV. The most frequently reported activity in either group was receptive penis to vagina sex but there was no difference between the groups in the proportion reporting receptive penis to vagina sex ($p = .0204$). The proportion of cisgender participants who reported receptive mouth to penis sex was two times (40.1%) the proportion of TGNB participants (20.1%) ($p < .0001$). Similarly, the proportion of cisgender participants who reported receptive mouth to vagina sex was two times (32.6%) the proportion of TGNB participants (16.1%) and the proportion of cisgender participants who reported receptive mouth to anus sex was two times (35.0%) the proportion of TGNB participants (15.5%) ($p < .0001$).

HPV Vaccination Rates

More TGNB participants reported ever receiving HPV vaccine (46.2%) compared to cisgender (38.8%) ($p < .0001$) (Table 4.3). A small proportion of TGNB participants (1.4%) and cisgender participants (0.5%) reported that the doctor refused to give them the HPV vaccine when they requested it ($p < .0001$). There were 2,213 participants who reported ever receiving HPV vaccine (39.9%). TGNB and cisgender participants did not differ in the proportion of each group that initiated HPV vaccine (*e.g.*, received 1-dose) versus completed HPV vaccine (*e.g.*, received 3-doses). Greater than 90% of both groups had heard of HPV (Table 4.4)

Prevalence of Receipt of HPV Vaccine

The prevalence (PR 1.2; 95% CI, 1.1-1.3) of receiving HPV vaccine ever was 1.2 times greater among TGNB participants than cisgender participants (Table 4.5). The prevalence (PR 1.1; 95% CI, 1.1-1.2) of receiving HPV vaccine ever was also 1.1 times greater among TGNB participants who were born with female organs compared to cisgender females who were born with female organs. The prevalence (PR 2.4; 95% CI, 2.0-2.8) of ever receiving HPV vaccine was 2.4 times greater among transgender men who were assigned female at birth (AFAB) compared to transgender women who were assigned male at birth (AMAB). Similarly, the prevalence (PR 2.1; 95% CI, 1.9-2.3) of receiving HPV vaccine ever was 2.1 times greater among cisgender sexual minority females compared to cisgender sexual minority males. The prevalence (PR 1.1; 95% CI, 1.1-1.2) of ever receiving HPV vaccine was 1.1 times greater among TGNB participants with female organs now and assigned female at birth compared to cisgender participants with female organs now and assigned female at birth.

Across all comparison groups we observed no difference in vaccine initiation (*e.g,* received 1-dose) and no difference in vaccine completion (*e.g.*, received 3-doses). The only

remaining notable difference in vaccination receipt was observed among transgender nonbinary AFAB, for whom the prevalence (PR 2.0; 95% CI, 1.6-2.5) of receiving HPV vaccine ever was two times greater than transgender nonbinary AMAB. However, we observed no differences in HPV vaccine receipt comparing transgender nonbinary participants with transgender binary participants; and no differences in vaccine receipt when comparing transmasculine participants with transfeminine participants.

Discussion

Our study found that in a sample of 5,500 SGM people participating in a large national online cohort, 2,213 (41.1%) participants ever received any doses of the HPV vaccine and of the participants who received the HPV vaccine, 121 (5.5%) initiated (*e.g.*, received 1-dose) and 1,561 (70.5%) completed (e.g., received 3-doses). Our finding that transgender men assigned female (AFAB) at birth were more likely to have received HPV vaccine than transgender women assigned male at birth (AMAB) is consistent with gender disparities that date back to the introduction of the HPV vaccine in 2006 and this was mirrored in cisgender participants. In the general population, males continue to lag females in HPV vaccination rates and this lag is thought to be related to population effects from the original recommendation that limited vaccination to girls (Daley et al., 2017; Williams et al., 2017). Moreover, our observed difference in vaccination between transgender AFAB and AMAB is similar studies of HPV vaccination in sexual minority people such as gay men who have been shown to have vaccination initiation rates as low as 13% compared to 47% in studies of sexual minority women (Agenor, Peitzmeier, et al., 2016; Reiter et al., 2015).

Although we did not find any differences in vaccine initiation and vaccine completion, we did find that across all groups that greater than 80% of participants completed 3-doses of

vaccine. This runs counter to studies that show decreased vaccine completion in both the general population and in sexual minority communities alike (Agenor, Peitzmeier, et al., 2016; Apaydin, Fontenot, Borba, et al., 2018; Williams et al., 2017). Both TGNB and cisgender sexual minority participants in our sample demonstrated other health-promoting behaviors that may have contributed to their high rates of HPV vaccine completion. The majority had a PCP and saw them in the last year. The majority had also received at least two vaccines other than HPV with high proportions of both groups reporting that had received a vaccine for influenza and Hepatitis-B. The latter is notable because, like HPV vaccine, Hepatitis-B requires a similar 3-dose schedule. Studies among SGM communities have shown an increase in HPV vaccination when individuals receive other vaccines like Hepatitis A/B (Apaydin, Fontenot, Borba, et al., 2018).

Although both cisgender sexual minority and TGNB participants demonstrated increased engagement with health care and this may have contributed to their receipt of HPV vaccine, TGNB participants reported greater barriers to care overall. Our findings are consistent with studies that show that both TGNB and cisgender sexual minority people have been known to delay or not receive necessary care (Jaffee et al., 2016; Macapagal et al., 2016). However our finding that a greater proportion of TGNB participants put off seeing a health care provider because of concern they would be disrespected or mistreated compared to cisgender participants because of the considerably different primary reason given for putting off seeing health care providers. TGNB participants reported age as the main reason for putting off seeing their providers whereas cisgender participants reported gender identity as the main reason. TGNB people have been shown to experience discrimination and stigma which affects their engagement in health care (Grant et al., 2011). There is emerging evidence that TGNB older adults

experience increased barriers to care but this is an understudied area (Fredriksen-Goldsen et al., 2017; Fredriksen-Goldsen et al., 2014; Porter et al., 2016).

Limited conclusions can be drawn from the higher use of dating apps we observed among TGNB participants compared to cisgender participants and over half of both groups spent less than an hour using the apps. Studies have shown that use of dating apps in MSM has been associated with STIs (Beymer et al., 2014). However, dating apps and amount of time spent on apps has not been investigated in relation to vaccination.

Lastly, our findings regarding HPV risk activities establishes that both TGNB and cisgender participants in our sample engage in activities that increase risk for exposure to HPV-infection. HPV vaccine is ideally administered before sexual debut. The age mean of 17 years for both groups is the age when initiating the 3-dose 'catch-up' adult series is recommended if an adolescent has not received any doses. Our finding that cisgender participants in our sample reported twice the number lifetime sexual partners than TGNB may represent increased risk of exposure for cisgender people. However, a recent study that examined prevalence of HPV infection found that unvaccinated transgender women had a higher prevalence of anal HPV infection than cisgender MSM (Singh et al., 2019). Although our results showed that TGNB and cisgender participants reported similar prevalence of engaging in anal receptive sex, TGNB people had decreased prevalence of any type of anal/rectal cancer screening compared to cisgender participants. HIV-infection has been observed among TGNB people, especially transgender women, and co-infection with HIV is thought to increase the risk of HPV-associated rectal/anal cancer (Poteat et al., 2016; Quinn et al., 2015).

Strengths/Limitations

This study has several strengths. It is one of the first studies to investigate HPV vaccination initiation and completion in a large sample of TGNB people. It leverages an online national cohort of SGM people are being followed longitudinally. However, the study is not without its limitations. The descriptive nature of the study limits conclusions. Self-reporting of receipt of HPV vaccine is subject to recall bias. Although national, The PRIDE Study is an online convenience sample. The participants in the sample are not representative of TGNB and cisgender sexual minority people, especially given that almost all were White race and had greater than high school education attainment. Finally, the cross-sectional nature of the study limits our ability to derive any causal relationships.

Conclusion

In summary, in our cross-sectional study of participants in the 2018-19 PRIDE Study Annual Questionnaire, we found TGNB people had higher prevalence of ever receiving HPV vaccine compared with cisgender sexual minority people. Transgender men who were assigned female at birth had two times the prevalence of ever receiving HPV vaccine compared to transgender women who were assigned male sex at birth and this was also reflected among cisgender sexual minority females had over two times the prevalence of ever receiving HPV vaccine compared to cisgender sexual minority males. These findings suggest that independent of gender identity, HPV vaccine disparities based on assigned sex at birth continue to exist among SGM communities. However, our finding that the prevalence of ever receiving HPV vaccine was greater among TGNB participants who were born with female organs compared to cisgender sexual minority females suggests TGNB people who are born with female organs may engage differently in preventative services like HPV vaccination than sexual minority women.

We found no differences in HPV vaccination initiation and completion between TGNB and cisgender participants, but that majority of participants had achieved vaccine completion, which suggests a high degree of primary care engagement in The PRIDE Study sample. Future studies should consider a national probability sampling to improve knowledge of HPV vaccination receipt among TGNB communities.

Table 4. 1 Comparison groups

Comparison	Group	Reference
A1. TGNB all compared to: Cisgender all	TGNB (ALL) Administrative identification / stratified by gender identity (A2 ALL and A3 ALL)	CISGENDER (ALL) Administrative identification / stratified by gender identity (A2 ALL and A3 ALL)
A2. Transgender men compared to: Transgender women	Transgender Man SAAB (Female2) AND GENDERID (Genderqueer1 OR Transgender man3 OR Man2 OR Another gender identity6)	Transgender Woman SAAB (Male1) AND GENDERID (Genderqueer1 OR Transgender woman4 OR Woman5 OR Another gender identity6)
A3. Cisgender female compared to: Cisgender male	Cisgender Female SAAB (Female2) AND GENDERID (Woman5)	Cisgender Male SAAB (Male1) AND GENDERID (Man2)
B1. TGNB organs born female compared to: Cisgender female	GENDERID (Genderqueer1 OR Transgender man3 OR Transgender woman4 OR Man2 OR Another gender identity6) AND ORGANS_BORN (cervix1 OR ovaries2 OR uterus OR vagina7)	GENDERID (Woman5) AND ORGANS_BORN (cervix1 OR ovaries2 OR uterus6 OR vagina7)
B2. TGNB organs born male compared to: Cisgender male	GENDERID (Genderqueer1 OR Transgender man3 OR Transgender woman4 OR Woman5 OR Another gender identity6) AND ORGANS_BORN (penis3 OR prostate4 OR testicles5)	GENDERID (Man2) AND ORGANS_BORN (penis3 OR prostate4 OR testicles5)
C1. Organs born male + organs now female compared to: Organs born male + organs now male	ORGANS_BORN (penis3 OR prostate4 OR testicles5) AND ORGANS_NOW (vagina8)	ORGANS_BORN (cervix1 OR ovaries2 OR uterus6 OR vagina7) AND ORGANS_NOW (cervix2 OR ovaries3 OR uterus7, vagina8)
C2. Organs born female + organs now male compared to: Organs born male + organs now male	ORGANS_BORN (cervix1 OR ovaries2 OR uterus6 OR vagina7) AND ORGANS_NOW (penis4 OR testicles6)	ORGANS_BORN (penis3 OR prostate4 OR testicles5) AND ORGANS_NOW (penis4 OR prostate5 OR testicles6)
D1. TGNB + Organs Now Female + AFAB compared to: Cisgender + Organs now female +AFAB	GENDERID (Genderqueer1 OR Transgender Man3 OR Transgender Woman4 OR Another gender identity6) AND ORGANS_NOW (cervix2 OR ovaries3 OR uterus7 OR vagina8) AND SAAB (Female2)	GENDERID (Woman5) AND ORGANSNOW (cervix2 OR ovaries3 OR uterus7 OR vagina8) AND SAAB (Female2)

Comparison	Group	Reference
D2. TGNB + Organs Now + Assigned Male at Birth (AMAB) compared to:	GENDERID (Genderqueer1 OR Transgender Man3 OR Transgender Woman4 OR Another gender identity6) AND ORGANS_NOW (vagina8) AND SAAB (Male1)	GENDERID (Man2) AND ORGANS_NOW (penis4 OR prostate5 OR testicles6) AND SAAB (Male1)
E1. Binary Identity Transmasculine ALL compared to: Transfeminine ALL	GENDERID (Genderqueer1 OR Transgender Man3 OR Another gender identity6) AND LIVEGEN (Man1) OR GENDERID (Man3) AND SAAB (Female2) AND LIVEGEN (Man1)	GENDERID (Genderqueer1 OR Transgender Man3 OR Another Gender Identity6) AND LIVEGEN (Woman2) OR GENDERID (Woman5) AND SAAB (Male1) AND LIVEGEN (Woman2)
F1. Nonbinary Identity Nonbinary + AFAB compared to: Nonbinary + AMAB	GENDERID (Genderqueer1 OR Another Gender Identity6) OR LIVEGEN (Sometimes man / sometimes woman3 OR Third gender other than man or woman4) AND SAAB (Female2)	GENDERID (Genderqueer1 OR Another Gender Identity6) OR LIVEGEN (Sometimes man / sometimes woman3 OR Third gender other than man or woman4) AND SAAB (Male1)
F2. Transgender Nonbinary ALL compared to: Transgender Binary ALL	(F1 ALL)	(E1 ALL)

AFAB (Assigned Female at Birth)
AMAB (Assigned Male at Birth)
SAAB (Sex Assigned at Birth)
TGNB (Transgender and Gender Nonbinary)

Table 4. 2 Participant characteristics

(*N*=5,500)		Total		TGNB ALL		CISGENDER ALL		
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	**X^2**	***p*-value**
DEMOGRAPHIC								
	5,500	(100)	1,691	(31.0)	3,859	(69.5)	846.9	<.0001
Sexual Orientation								
Asexual	548	(9.9)	319	(18.9)	229	(5.9)	220.9	<.0001
Bisexual	1,596	(28.8)	496	(29.3)	1,100	(28.5)	0.4	.5310
Gay	1,951	(35.2)	284	(16.8)	1,667	(43.2)	359.6	<.0001
Lesbian	1,227	(22.1)	227	(13.4)	1,000	(25.9)	106.5	<.0001
Pansexual	880	(15.9)	426	(25.2)	454	(11.8)	158.9	<.0001
Queer	2,136	(38.5)	982	(58.1)	1,154	(29.9)	394.1	<.0001
Questioning	154	(2.8)	77	(4.6)	77	(2.0)	28.6	<.0001
Same-gender loving	278	(5.0)	105	(6.2)	173	(4.5)	7.4	.0067
Straight/Heterosexual	99	(1.8)	83	(4.9)	16	(16.2)	135.5	<.0001
Another sexual orientation	197	(3.6)	124	(7.3)	73	(1.9)	101.7	<.0001
Multiple categories selected								
Gender Identity								
Genderqueer	945	(17.0)	674	(39.9)	271	(7.0)	897.3	<.0001
Man	1,873	(33.8)	269	(15.9)	1,604	(41.6)	346.2	<.0001
Transgender man	573	(10.3)	566	(33.5)	7	(0.2)	1,407.3	<.0001
Transgender woman	275	(5.0)	271	(16.0)	4	(0.1)	633.0	<.0001
Woman	2,385	(43.0)	121	(7.2)	2,264	(58.7)	1,273.1	<.0001
Another gender identity	676	(12.2)	577	(34.1)	99	(2.6)	1,094.6	<.0001
Lived gender day-to-day (missing=142)								
Man	2,115	(39.1)	569	(34.3)	1,546	(41.2)		<.0001*
Woman	2,581	(47.7)	429	(25.9)	2,152	(57.4)		
Sometimes man/woman*	135	(2.5)	123	(7.4)	12	(0.3)		
Third gender or something other than man or woman	577	(10.7)	538	(32.4)	39	(1.0)		
Assigned sex at birth								
Male	1,967	(35.4)	369	(21.8)	1,598	(41.4)	197.2	<.0001
Female	3,583	(64.6)	1,322	(78.2)	2,261	(58.6)		
Intersex	56	(1.0)	48	(0.9)	8	(0.2)		<.0001*

(*N*=5,500)		Total		TGNB ALL		CISGENDER ALL		
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	**X^2**	***p*-value**
Organs born with								
Cervix	3,483	(62.8)	1,286	(76.1)	2,197	(56.9)	183.9	<.0001
Ovaries	3,487	(62.8)	1,288	(76.2)	2,199	(57.0)	185.3	<.0001
Penis/Phallus (not prosthetic)	1,852	(33.4)	353	(20.9)	1,499	(38.9)	170.9	<.0001
Prostate	1,859	(33.5)	355	(21.0)	1,504	(39.0)	170.6	<.0001
Testicles	1,903	(34.3)	363	(21.5)	1,540	(39.0)	177.4	<.0001
Uterus/Womb	3,481	(62.7)	1,290	(76.3)	2,191	(56.8)	191.4	<.0001
Vagina/Frontal genital opening	3,483	(62.8)	1,288	(76.2)	2,195	(56.9)	187.1	<.0001
Organs now								
Breasts or breast tissue1	3,390	(61.1)	1,181	(69.8)	2,209	(57.2)	79.0	<.0001
Cervix2	3,253	(58.6)	1,139	(67.4)	2,114	(54.8)	77.1	<.0001
Ovaries3	3,290	(59.3)	1,158	(68.5)	2,132	(55.3)	85.8	<.0001
Penis/Phallus (not prosthetic)4	1,884	(34.0)	330	(19.5)	1,554	(40.3)	225.5	<.0001
Prostate 5	1,819	(32.8)	322	(19.1)	1,497	(38.8)	207.8	<.0001
Testicles6	1,826	(32.9)	288	(17.0)	1,538	(39.9)	277.1	<.0001
Uterus/Womb7	3,223	(58.1)	1,133	(67.0)	2,090	(54.2)	80.1	<.0001
Vagina/Frontal genital opening8	3,486	(62.8)	1,299	(76.9)	2,187	(56.7)	205.2	<.0001
Race/ethnicity (missing=1)								
American Indian/Alaska Native	8	(0.1)	3	(0.2)	5	(0.1)		.0002*
Asian	157	(2.8)	41	(2.4)	116	(3.0)		
Black, African American, African	99	(1.8)	23	(1.4)	76	(2.0)		
Hispanic, Latino, Spanish	132	(2.4)	27	(1.6)	105	(2.7)		
Middle Eastern, North African	16	(0.2)	4	(0.2)	12	(0.3)		
Native Hawaiian, Pacific Islander	2	(0.04)	0	(0)	2	(0.1)		
White	4,536	(81.7)	1,367	(80.8)	3,169	(82.1)		
Other (None fully describe me)	35	(0.6)	18	(1.1)	17	(0.4)		
Mixed (>1 race/ethnicity selected)	564	(10.2)	208	(12.3)	356	(9.2)		
In a Relationship (missing=5)								
Yes	3,357	(62.1)	975	(58.7)	2,382	(63.6)	11.5	.0007
No	2,052	(37.9)	686	(41.3)	1,366	(36.5)		
Legal marital status (missing=5)								
Married	1,465	(27.1)	371	(22.3)	1,094	(29.2)		<.0001*

(*N*=5,500)			TGNB		CISGENDER			
		Total		ALL		ALL		
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	X^2	***p*-value**
Legally recognized civil union	7	(0.1)	2	(0.1)	5	(0.1)		
Registered domestic partnership	83	(1.5)	16	(1.0)	67	(1.8)		
Widowed	49	(0.9)	12	(0.7)	37	(1.0)		
Divorced	336	(6.2)	126	(7.6)	210	(5.6)		
Separated	56	(1.0)	23	(1.4)	33	(0.9)		
Single, never married	3,413	(63.1)	1,112	(66.9)	2,301	(61.4)		
Work in one or more paid jobs?								
Yes	4,119	(75.9)	1,159	(69.7)	2,960	(78.6)	50.7	<.0001
No	1,310	(24.1)	505	(30.4)	805	(21.4)		
Occupation (missing=1,449)								
Employed >=40 hr/week	2,231	(54.4)	519	(44.9)	1,712	(58.1)		<.0001*
Employed 1-39 hr/week	529	(12.9)	190	(16.4)	339	(11.5)		
Temporarily employed	17	(0.4)	9	(0.8)	8	(0.3)		
Self-employed	112	(2.7)	24	(2.1)	88	(3.0)		
Not employed, looking	56	(1.4)	9	(0.8)	47	(1.6)		
Not employed, not looking	5	(0.1)	1	(0.1)	4	(0.1)		
Homemaker	0	(0)	0	(0)	0	(0)		
Student full time	2	(0.1)	0	(0.)	2	(0.1)		
Student part time	5	(0.1)	1	(0.1)	4	(0.1)		
Disabled, not able to work	2	(0.1)	0	(0)	2	(0.1)		
Retired	1	(0.02)	0	(0)	1	(0.03)		
>1 Occupation	1,148	(28.0)	404	(35.0)	744	(25.3)		
Income 2019 tax year (missing=242)								
$0	374	(7.1)	184	(11.3)	190	(5.2)	299.1	<.0001
$1 – 10,000	967	(18.2)	418	(25.6)	549	(15.0)		
$10,001 – 20,000	672	(12.7)	261	(16.0)	411	(11.2)		
$20,001 – 30,000	573	(10.8)	184	(11.3)	389	(10.6)		
$30,001 – 40,000	558	(10.5)	171	(10.5)	387	(10.5)		
$40,001 – 50,000	442	(8.3)	101	(6.2)	341	(9.3)		
$50,001 – 60,000	398	(7.5)	87	(5.3)	311	(5.3)		
$60,001 – 70,000	266	(5.0)	58	(3.6)	208	(3.6)		
$70,001 – 80,000	186	(3.5)	41	(2.5)	145	(2.5)		
$80,001 – 90,000	161	(3.0)	28	(1.7)	133	(1.7)		
$90,001 – 100,000	139	(2.6)	21	(1.3)	118	(1.3)		

(*N*=5,500)		Total		TGNB ALL		CISGENDER ALL		
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	X^2	***p*-value**
$100,000+	572	(10.8)	81	(5.0)	491	(5.0)		
Education attainment								
High school or less	426	(7.7)	170	(10.1)	256	(6.6)	19.4	<.0001
More than high school	5,214	(92.3)	1,521	(90.0)	3,603	(93.4)		
Census region resides in (missing=62)								
Region 1 – Northeast	1,094	(19.9)	360	(21.7)	734	(19.2)	10.0	.0184
Region 2 – Midwest	1,115	(20.3)	357	(21.5)	758	(19.8)		
Region 3 – South	1,473	(26.8)	408	(24.5)	1,065	(27.8)		
Region 4 - West	1,806	(32.9)	538	(32.4)	1,268	(33.2)		
SITUATION – BARRIERS TO CARE								
% Health Care Providers aware of your Sexual Orientation (missing=443)								
0 – None	690	(13.5)	200	(13.8)	490	(13.4)	69.9	<.0001
50%	492	(9.63)	144	(9.9)	348	(9.5)		
100%	2,022	(39.6)	474	(32.7)	1,548	(42.3)		
% Health care providers aware of your Gender Identity (missing 3,625)								
0 – None	468	(24.3)	298	(18.5)	170	(54.1)	225.0	<.0001
50%	153	(8.0)	125	(7.8)	28	(8.9)		
100%	679	(35.3)	642	(39.9)	37	(11.8)		
Denied or given lower quality medical care EVER (missing = 174)	1,173	(21.8)	593	(35.9)	580	(15.6)	276.4	<.0001
Reason why denied/given lower quality medical care EVER (N=1,172) missing=1								
0 None of these	26	(2.2)	13	(2.2)	13	(2.2)	271.7	<.0001
1 Sexual orientation	10	(0.9)	5	(0.8)	5	(0.9)		
2 Gender identity	90	(7.7)	19	(3.2)	71	(12.2)		
3 Gender expression	9	(0.8)	8	(1.4)	1	(0.2)		
4 Race and/or ethnicity	117	(10.0)	99	(16.7)	18	(3.1)		
5 Age	6	(0.5)	1	(0.2)	5	(0.2)		

(*N*=5,500)		Total		TGNB ALL		CISGENDER ALL		
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	X^2	***p*-value**
6 Ability/disability status	190	(16.2)	19	(3.2)	171	(3.2)		
7 Something else	86	(7.3)	28	(4.7)	58	(4.7)		
8 Body size, weight or shape	22	(1.9)	9	(1.5)	13	(1.5)		
9 >1 reason selected	616	(53.0)	391	(66.1)	225	(66.1)		
Delayed medical care in past year (missing=147)	1,157	(21.4)	525	(31.9)	632	(16.8)	155.0	<.0001
Reason delayed care in past year (N=1,154) missing=3								
0 Couldn't afford care	107	(9.3)	29	(5.5)	78	(12.4)	35.9	.0003
1 Insurance company wouldn't cover	168	(14.6)	76	(14.5)	92	(14.6)		
2 Health care provider refused insurance plan	10	(0.9)	4	(0.8)	6	(1.0)		
3 Problems getting to provider's office	4	(0.4)	1	(0.2)	3	(0.5)		
4 Speak a different language	116	(10.1)	41	(7.8)	75	(11.9)		
5 Couldn't get time off work or school	0	(0)	0	(0)	0	(0)		
6 Don't know where to go to get care	11	(1.0)	4	(0.8)	7	(1.1)		
7 Was refused services	4	(0.4)	3	(0.6)	1	(0.2)		
8 Couldn't get childcare	7	(0.6)	4	(0.8)	3	(0.5)		
9 Didn't have time or took too long	2	(0.2)	0	(0)	2	(0.3)		
10 Other	3	(0.3)	3	(0.6)	0	(0)		
11 Thought would be mistreated/disrespected on basis of sexual orientation	0	(0)	0	(0)	0	(0)		
12 Thought would be mistreated/disrespected on basis of gender identity	22	(1.9)	7	(1.3)	15	(2.4)		
13 Provider could not schedule in a timely fashion	114	(9.9)	56	(10.7)	58	(9.2)		
14 >1 reason selected	586	(50.8)	296	(56.5)	290	(46.0)		
Did not see provider because thought would be disrespected / mistreated in past year (missing=157)	980	(18.2)	572	(34.5)	408	(10.9)	429.9	<.0001
Reason put off seeing health care provider because concerned would be disrespected/mistreated (N=980) missing=23								
Sexual orientation	33	(3.5)	12	(2.1)	21	(5.3)	265.4	<.0001
Gender Identity	3	(0.3)	2	(0.4)	1	(0.3)		
Gender Expression	99	(10.3)	21	(3.7)	78	(19.7)		
Race and/or ethnicity	24	(2.5)	18	(3.2)	6	(1.5)		
Age	339	(35.4)	310	(55.3)	29	(7.3)		

(*N*=5,500)		Total		TGNB ALL		CISGENDER ALL		
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	X^2	***p*-value**
Ability/disability status	15	(1.6)	8	(1.4)	7	(1.8)		
Something else	340	(35.5)	152	(27.1)	188	(47.5)		
Body size, weight, or shape	104	(10.9)	38	(6.8)	66	(16.7)		
Unable to obtain medical care, test or treatments you or a health care provider deemed necessary in the past year (missing=143)	719	(13.3)	352	(21.4)	367	(9.8)	133.6	<.0001
Main reason why unable to get medical care, tests, or treatments? (N=713) missing=6								
0 Couldn't afford	193	(27.1)	93	(26.8)	100	(27.3)	33.1	.0009
1 Insurance company wouldn't cover care	249	(34.9)	116	(33.4)	133	(36.3)		
2 Doctor refused to accept insurance plan	24	(3.4)	8	(2.3)	16	(4.4)		
3 Problems getting to doctor's office	16	(2.2)	8	(2.3)	8	(2.2)		
4 I speak a different language								
5 Couldn't get time off work or school	26	(3.7)	12	(3.5)	14	(3.8)		
6 Don't know where to go to get care	25	(3.5)	18	(5.2)	7	(1.9)		
7 Was refused services	34	(4.8)	17	(4.9)	17	(4.6)		
8 Couldn't get child care	1	(0.1)	0	(0)	1	(0)		
9 Didn't have time or took too long	20	(2.8)	7	(2.0)	13	(2.0)		
10 Other	68	(9.5)	35	(10.1)	33	(9.0)		
11 Thought would be mistreated/disrespected on basis of sexual orientation	3	(0.4)	0	(0)	3	(0.8)		
12 Thought would be mistreated/disrespected on basis of gender identity	21	(3.0)	20	(5.8)	1	(0.3)		
13 Provider could not schedule in timely fashion	33	(4.6)	13	(3.8)	20	(5.5)		
How often avoid talking about topics related to or indicating your sexual orientation with health care providers (missing=441)								
0 Never	2,772	(54.3)	737	(50.8)	2,035	(55.6)	32.1	.0004
5 Half the time	559	(10.9)	163	(11.2)	396	(10.8)		
10 Always	250	(4.9)	80	(5.5)	170	(4.7)		
How often avoid talking about topics relating to gender/gender identity with health care providers (%) (missing=3,628)								

(*N*=5,500)		Total		TGNB ALL		CISGENDER ALL		
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	**X^2**	***p*-value**
0 Never	683	(35.5)	599	(37.2)	84	(26.8)	73.6	<.0001
5 Half the time	269	(14.0)	234	(14.5	35	(11.2)		
10 Always	342	(17.8)	239	(14.9)	103	(32.9)		
SITUATION – ACCESS TO CARE								
Have Primary Care Provider (PCP) (missing=282)	4,345	(82.5)	1,297	(82.0)	3,048	(82.7)	.3060	.5802
Saw PCP in past year (missing=1,251)	3,874	(90.1)	1,186	(92.3)	2,688	(89.2)	9.8	.0018
Went to provider/clinic for transgender care in past year (missing=150)	929	(17.2)	918	(55.8)	11	(1.2)	2,476.9	<.0001
Have ever taken hormones for gender affirmation (missing=132)	941	(17.4)	927	(56.2)	14	(0.3)	2,490.5	<.0001
Have health insurance (missing=213)	5,124	(96.0)	1,531	(94.3)	3,593	(96.8)	18.4	<.0001
Type of health insurance								
Medicaid/Medicare	645	(11.6)	241	(14.3)	404	(10.5)	21.6	<.0001
Private Insurance	4,612	(83.1)	1,346	(79.6)	3,266	(84.6)		
Other	293	(5.3)	104	(6.2)	189	(4.9)		
SITUATION – PREVENTIVE CARE								
Health in general (PROMIS-1) (missing=129)								
Excellent	204	(3.8)	104	(6.3)	100	(2.7)	136.2	<.0001
Very good	896	(16.5)	361	(21.8)	535	(14.2)		
Good	1,943	(35.8)	616	(37.3)	1,327	(35.2)		
Fair	1,880	(34.7)	477	(28.9)	1,403	(37.2)		
Poor	498	(9.2)	95	(5.8)	403	(10.7)		
HIV test ever (missing=341)								
Yes	3,317	(63.7)	946	(57.7)	2,371	(66.4)	43.3	<.0001
No	1,660	(31.9)	591	(36.1)	1,069	(29.9)		
Don’t know	232	(4.5)	102	(6.2)	130	(3.6)		
Ever had influenza vaccine (missing=161)								
Yes	3,753	(69.6)	1,035	(62.9)	2,718	(72.6)	53.3	<.0001

(*N*=5,500)			TGNB		CISGENDER			
		Total		ALL		ALL		
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	X^2	***p*-value**
No	1,603	(29.8)	595	(36.2)	1,008	(26.9)		
Don't know	33	(0.6)	16	(1.0)	17	(0.5)		
Ever had Hepatitis A vaccine (missing=164)								
Yes	3,006	(55.8)	844	(51.2)	2,162	(57.8)	39.5	<.0001
No	898	(16.7)	255	(15.5)	643	(17.2)		
Don't know	1,482	(27.5)	548	(33.3)	934	(25.0)		
Ever had Hepatitis B vaccine (missing=165)								
Yes	4,039	(75.0)	1,187	(72.2)	2,852	(76.3)	28.1	<.0001
No	577	(10.7)	161	(9.8)	416	(11.1)		
Don't know	769	(14.3)	297	(18.1)	472	(12.6)		
Ever had pneumococcal vaccine (missing=159)								
Yes	2,140	(39.7)	1,515	(40.5)	625	(38.0)	36.5	<.0001
No	2,071	(38.4)	578	(35.1)	1,493	(39.9)		
Don't know	1,180	(21.9)	444	(27.0)	736	(19.7)		
Ever had shingles vaccine (missing=164)								
Yes	865	(16.1)	241	(14.6)	624	(16.7)	26.3	<.0001
No	3,473	(64.5)	1,017	(61.8)	2,456	(65.7)		
Don't know	1,048	(19.5)	388	(23.6)	660	(17.7)		
Ever had a cervical Pap? (missing=2,019)								
Yes	2,661	(75.4)	874	(65.3)	1,787	(81.5)	117.9	<.0001
No	841	(23.8)	451	(33.7)	390	(17.8)		
Don't know	29	0.8)	13	(1.0)	16	(0.7)		
HPV test with recent Pap (missing=189)								
Yes	471	(8.8)	91	(5.6)	380	(10.2)	30.8	<.0001
No	4,890	(91.2)	1,548	(94.5)	3,342	(89.8)		
Ever had anal/rectal cancer screening (missing=228)								
Digital anal rectal exam	761	(14.3)	147	(9.0)	614	(16.6)	113.5	<.0001
Anal HPV test	74	(1.4)	21	(1.3)	53	(1.4)		
Anal Pap smear	28	(0.5)	8	(0.5)	20	(0.5)		

(*N*=5,500)				TGNB		CISGENDER		
		Total		ALL		ALL		
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	X^2	***p*-value**
High-Resolution Anoscopy (HRA)	21	(0.4)	7	(0.4)	14	(0.4)		
Had multiple types of anal cancer screening	374	(7.0)	56	(3.4)	318	(8.6)		
None of these	3,962	(74.5)	1,354	(83.2)	2,608	(70.6)		
Don't know	102	(1.9)	35	(2.2)	67	(1.8)		
INTERNET USE								
App Use (missing=644)								
Use 1 dating app (*e.g.,* Adam4Adam, Tinder, etc.)	3,344	(68.2)	1,106	(73.3)	2,238	(65.9)	226.0	<.0001
Use multiple dating apps	1,562	(31.8)	404	(26.8)	1,158	(34.1)		
Average Time Spent on dating apps for those that use them (missing=2,706)								
Less than 1 hour per week	1,268	(57.6)	427	(57.6)	841	(53.7)	37.3	<.0001
1-6 hours per per week	662	(30.1)	158	(24.9)	504	(32.2)		
1 hour per day	161	(7.3)	32	(5.0)	129	(8.2)		
2 hours per day	76	(3.5)	11	(1.7)	65	(4.2)		
3 or more hours per day	33	(1.5)	7	(1.1)	26	(1.7)		
SITUATION –RISK FOR HPV								
HPV history of genital warts (ever)(missing=226)	314	(5.9)	44	(2.7)	270	(7.3)	43.1	<.0001
Sexual activity (ever)(N=1,235)	836	(67.7)	339	(66.6)	794	(68.5)	0.5	.4924
Receptive oral sex (N=833)								
Mouth to penis	267	(32.1)	68	(20.1)	199	(40.1)	51.4	<.0001
Mouth to vagina	190	(22.8)	110	(32.6)	80	(16.1)		
Both mouth to penis and vagina	281	(33.7)	113	(33.5)	168	(33.9)		
Never receptive penis/vagina oral sex	95	(11.4)	46	(13.7)	49	(9.9)		
Receptive oral sex – mouth to anus (N=829)	225	(27.1)	52	(15.5)	173	(35.0)	38.4	<.0001
Receptive vaginal - penis to vagina (N=559)	341	(61.0)	138	(55.7)	203	(65.3)	5.4	.0204
Receptive vaginal – vagina to vagina (N=826)	284	(34.4)	103	(30.5)	181	(37.1)	3.9	.0490
Receptive anal sex – penis to anus (N=556)	162	(29.1)	67	(27.4)	95	(30.6)	0.7	.4098

(*N*=5,500)		Total		TGNB ALL		CISGENDER ALL		
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	***X*²**	***p*-value**
Age at Sexual Debut & Lifetime Sexual Partners (see below)								

Continuous Variables		Total		TGNB ALL		CISGENDER ALL			
	Range	**Mean**	**(*SD*)**	**Mean**	**(*SD*)**	**Mean**	**(*SD*)**	***t*-test**	***p*-value**
SITUATION - HPV RISK									
Age at sexual debut[+]	2-35	17.6	5.0	17.3	4.8	17.8	5.2	814	.2224
Lifetime sexual partners[++]	1-54	13.1	16.5	8.6	12.1	16.1	18.3	822	<.0001
DEMOGRAPHICS									
Age[+++]	18 – 81	34.8	13.4	31.3	11.4	36.3	13.9	3,856	<.0001

*Fishers Exact Test for cells <30

[+]Age at sexual debut median 18 (interquartile range [IQR], 15-20)

[++]Lifetime sexual partners media 6 (interquartile range [IQR], 2-15)

[+++]Age median 31 (interquartile range [IQR], 25-41)

Outliers greater than or less than 1.5*[IQR] were removed prior to calculating mean and median

Table 4. 3 HPV Vaccine & Number of Doses

(*N*=5,550)		Total		TGNB ALL		CISGENDER ALL		
Item	***n***	**(%)**	***n***	**(%)**	***n***	**(%)**	X^2	***p*-value**
Ever received HPV vaccine? (missing=161)								
Yes	2,213	(41.1)	761	(46.2)	1,452	(38.8)	66.4	<.0001
No	2,631	(48.8)	676	(41.0)	1,955	(52.2)		
Doctor refused when asked	126	(2.3)	38	(2.3)	88	(2.4)		
I don't know	419	(7.8)	172	(10.4)	247	(6.6)		
Reported doses ever received HPV vaccine (N=2,209) (missing=4)								
HPV Vaccine [1-dose]	121	(5.5)	44	(5.8)	77	(5.3)	13.2	.0042
HPV Vaccine [2-doses]	219	(9.9)	83	(10.9)	136	(9.4)		
HPV Vaccine [3-doses]	1,561	(70.7)	502	(66.1)	1,059	(73.0)		
Don't know / cannot recall	308	(13.9)	130	(17.1)	178	(12.3)		

Table 4. 4 HPV Knowledge

(N=5,550)		Total		TGNB ALL		CISGENDER ALL		
Item	***n***	**(%)**	***n***	**(%)**	***n***	**(%)**	X^2	***p*-value**
Ever heard of HPV? (missing=2,232)								
Yes	3,044	(91.7)	1,066	(90.9)	1,978	(92.2)		.0317
No	247	(7.4)	91	(7.8)	156	(7.3)		
I don't know	27	(0.8)	16	(1.4)	11	(0.5)		

Table 4. 5 Receipt of HPV Vaccine

	Total		Group		Ref			
Group / Receipt of Vaccine	***n***	**(%)**	***n***	**(%)**	***n***	**(%)**	**PR**	**95% CI**
A1. Transgender ALL vs Cisgender ALL				**TGNB**		**Cisgender**		
Received HPV vaccine (ever) (*n*=4,970)	2,213	(44.5)	2,213	(44.5)	1,452	(41.6)	**1.2**	**1.2-1.3**
Initiated/Completed (*n*=2,213)								
Initiated (1-dose)	121	(5.5)	44	(5.8)	77	(5.3)	1.1	0.8-1.6
Completed (3-doses)	1,561	(70.5)	502	(66.0)	1,059	(72.9)	0.9	0.9-1.0
A2. Gender Identity (Transgender)				**Transman SAAB Female**		**Transwoman SAAB Male**		
Received HPV vaccine (*n*=1,779)	926	(52.1)	836	(58.9)	90	(25.0)	**2.4**	**2.0-2.8**
Initiated/Completed (n=771)								
Initiated (1-dose)	57	(7.8)	49	(7.1)	8	(10.5)	0.7	0.3-1.3
Completed (3-doses)	615	(80.0)	566	(81.4)	49	(64.5)	1.2	1.0-1.5
A3. Gender Identity (Cisgender)				**Cisgender SM Female**		**Cisgender SM Male**		
Received HPV vaccine (ever) (*n*=3,495)	1,452	(41.6)	1,098	(52.6)	354	(25.2)	**2.1**	**1.9-2.3**
Initiated/Completed (*n*=1,272)								
Initiated (1-dose)	77	(6.1)	51	(5.3)	26	(8.4)	0.6	0.4-1.0
Completed (3-doses)	1,059	(83.3)	815	(84.7)	244	(78.7)	1.0	1.1-1.2
B1. Gender Identity + Organs Born With				**TGNB Organs Born Female**		**Cisgender Female Organs Born Female**		
Received HPV vaccine (ever) (*n*=3,261)	1,783	(54.7)	687	(58.6)	1,096	(52.5)	**1.1**	**1.1-1.2**
Initiated/Completed (*n*=1,528)								
Initiated (1-dose)	89	(5.8)	28	(6.7)	51	(5.3)	1.2	0.8-1.8
Completed (3-doses)	1,274	(83.4)	461	(81.2)	813	(84.7)	0.9	0.9-1.0

Group / Receipt of Vaccine	*n*	Total (%)	*n*	Group (%)	*n*	Ref (%)	PR	95% CI
B2. Gender Identity + Organs Born With				**TGNB Organs Born Male**		**Cisgender Male Organs Born Male**		
Received HPV vaccine (ever)(*n*=1,717)	432	(25.2)	76	(24.4)	356	(25.3)	1.0	0.8-1.2
Initiated/Completed (*n*=375)								
Initiated (1-dose)	32	(8.5)	6	(9.5)	26	(8.3)	1.1	0.5-2.5
Completed (3-doses)	289	(77.1)	43	(68.3)	246	(78.9)	0.8	0.7-1.0
C1. Organs Born With			**Organs Born Female Organs Now Male**		**Organs Born Female Organs Now Female**			
Received HPV vaccine (ever)(*n*=3,245)	1,777	(54.8)	7	(43.8)	1,770	(54.8)	0.8	0.5-1.4
Initiated/Completed (*n*=1,523)								
Initiated (1-dose)	89	(5.8)	0	(0)	89	(5.9)	-	-
Completed (3-doses)	1,270	(83.4)	6	(85.7)	1,264	(83.4)	1.2	0.9-1.6
C2. Organs Born With			**Organs Born Male Organs Now Female**		**Organs Born Male Organs Now Male**			
Received HPV vaccine (ever)(*n*=1,709)	428	(24.0)	5	(19.2)	423	(25.1)	0.8	0.4-1.7
Initiated/Completed (*n*=374)								
Initiated (1-dose)	32	(8.6)	1	(20.0)	31	(8.4)	2.7	0.5-16.3
Completed (3-doses)	288	(77.0)	2	(40.0)	286	(77.5)	0.6	0.2-1.7
D1. Gender Identity + Organs Now + SAAB				**TGNB Organs Now Female AFAB**		**Cisgender Organs Now Female AFAB**		
Received HPV vaccine (ever)(*n*=3,195)	1,751	(54.8)	656	(58.9)	1,095	(52.6)	**1.1**	**1.1-1.2**
Initiated/Completed (*n*=1,501)								
Initiated (1-dose)	89	(5.9)	38	(7.0)	51	(5.3)	1.2	0.8-1.9
Completed (3-doses)	1,253	(83.5)	440	(81.2)	813	(84.8)	0.9	0.8-1.0

Group / Receipt of Vaccine	Total *n*	Total (%)	Group *n*	Group (%)	Ref *n*	Ref (%)	PR	95% CI
D2. Gender Identity + Organs Now + SAAB			**TGNB Organs Now Male AMAB**		**Cisgender Organs Now Male AMAB**			
Received HPV vaccine (ever)(N=1,443)	357	(24.7)	4	(10.0)	353	(25.2)	0.4	0.2-1.0
Initiated/Completed (*n*=313)								
Initiated (1-dose)	27	(8.6)	1	(25.0)	26	(8.4)	3.4	0.6-19.3
Completed (3-doses)	243	(77.6)	0	(0)	243	(78.6)	-	-
E1. Transgender Binary Identity			**Transmasculine**		**Transfeminine**			
Received HPV vaccine (ever)(*n*=987)	513	(52.0)	264	(53.8)	249	(50.2)	1.1	1.0-1.2
Initiated/Completed (*n*=432)								
Initiated (1-dose)	37	(8.6)	21	(9.5)	16	(7.6)	1.2	0.7-2.3
Completed (3-doses)	347	(80.3)	173	(77.9)	174	(82.9	0.9	0.8-1.1
F1. Transgender Nonbinary Identity			**Nonbinary AFAB**		**Nonbinary AMAB**			
Received HPV vaccine (ever)(*n*=1,249)	706	(56.5)	652	(60.8)	54	(30.7)	**2.0**	**1.6-2.5**
Initiated/Completed (*n* =594)								
Initiated (1-dose)	49	(8.3)	42	(7.7)	7	(14.3)	0.5	0.2-1.1
Completed (3-doses)	474	(79.8)	441	(80.9)	33	(67.4)	1.1	0.9-1.4
F2. Trans Nonbinary Identity ALL vs Trans Binary Identity ALL			**Trans Nonbinary ALL**		**Trans Binary ALL**			
Received HPV vaccine (ever)(N=1,638)	883	(53.9)	370	(56.8)	513	(52.0)	1.1	1.0-1.2
Initiated/Completed (*n*=740)								
Initiated (1-dose)	57	(7.7)	20	(6.5)	37	(8.6)	0.8	0.4-1.3
Completed (3-doses)	594	(80.3)	247	(80.2)	347	(80.3)	1.0	0.9-1.1

AFAB (Assigned Female at Birth), AMAB (Assigned Male at Birth), SM (Sexual Minority)
Robust Poisson method used to calculate PR (Prevalence Ratio)

Chapter 5: Human papillomavirus vaccination, online health information seeking, and health literacy among transgender and gender nonbinary people

The study in Chapter Five addresses the third aim of the dissertation to explore factors associated with HPV vaccination initiation and completion among TGNB people; particularly online health information seeking and eHealth literacy. The study is a cross-sectional analysis of a novel online survey of participants recruited from The PRIDE Study cohort.

Background

Sexual and gender minority (SGM) people are an understudied population who are vulnerable to poor health and include sexual minorities based on sexual orientation (*e.g.,* lesbian women, gay men, bisexual men and women) and gender minorities based on gender identity (*e.g.,* transgender, nonbinary and other gender-expansive people) (National Institutes of Health, 2019). The National Institutes of Health designated SGM people a health disparities population in acknowledgement of poor health outcomes and research gaps in these communities (Perez-Stable, 2016). Studies using data from the Health Information National Trends Survey found that sexual minority people are more likely to seek and be exposed to incidental health information online, more likely to watch online health videos on YouTube, and less likely to first seek health information from a physician compared to their heterosexual peers (Jabson et al., 2017; Langston et al., 2019; Lee et al., 2017). Although research about health information seeking and eHealth literacy (the ability to use electronic health information to make health decisions) has been explored in sexual minority people, these topics have not been explored among transgender and gender nonbinary (TGNB) people, who are estimated to number at least 1.4 million in the U.S

(Flores, 2016). Unlike cisgender sexual minority people whose gender identity matches their assigned sex at birth, TGNB people have gender identities/expressions that may not conform to their assigned sex at birth and may self-identify as transmen/women, transgender men/women or men/women (American Psychological Association, 2015; Institute of Medicine, 2011). Some TGNB people self-identify as nonbinary or genderqueer, terms used to describe people whose gender is not exclusively male or female, including those who identify with a gender other than male or female, as more than one gender, or as no gender (James, 2016).

For the purposes of this study, we use the terms transgender and gender nonbinary (TGNB) to encompass these communities, however we acknowledge that TGNB may not capture all that ways in which gender minority people express their identities. TGNB people have unique health information needs relating to their gender identity such as gender-affirming hormone management (Horvath et al., 2012). TGNB people report a higher prevalence of poor health and experience stigma and discrimination with healthcare providers based on their gender identity, resulting in poor health outcomes from delaying or deferring necessary care (Bradford et al., 2013; Jaffee et al., 2016; Macapagal et al., 2016; Meyer et al., 2017; Safer et al., 2016; Winter et al., 2016). For example, TGNB people with a cervix who are sexually active are at risk of HPV and yet have reduced rates of cervical cancer screening and increased time between recommended screening intervals compared to cisgender women (Peitzmeier, Khullar, et al., 2014; Peitzmeier, Reisner, et al., 2014). Although TGNB people have been shown to utilize the Internet for community building and information sharing (Shapiro, 2004), there is a paucity of research that explores online health information seeking among TGNB people and how this may be associated with health decision-making. The purpose of this study is to describe health

information seeking among a sample of TGNB people to explore how this may be associated with a preventative health behavior, human papillomavirus (HPV) vaccination.

Human papillomavirus (HPV) is the most common sexually-transmitted infection (STI) in adults in the United States with a prevalence of 79 million existing infections and incidence rate of 14 million new infections per year (Dunne et al., 2014). High-risk strains of HPV are associated with the majority of recto-anal, vagino-cervical, and oropharyngeal cancers (Centers for Disease Control and Prevention, 2013; Dunne et al., 2014). A vaccine to prevent HPV-infection was introduced in 2006. The Advisory Committee on Immunization Practices (ACIP) recommends two doses of vaccine starting at age 9-11 years and three adult "catch-up" doses for those who have not had received any vaccine doses by age 15-years. The national goal proposed in Healthy People 2020 was 80% vaccine completion for HPV (*e.g.*, received the full vaccination series, or all recommended doses based on age group) (Markowitz et al., 2014). The Centers for Disease Control and Prevention (CDC) estimates that only fifty-four percent of eligible adolescents have achieved vaccine completion and approximately 23 million young adults remain unvaccinated for HPV in the general population (Elam-Evans et al., 2020; Walker et al., 2017; Williams et al., 2017). In June 2019, ACIP expanded the recommended age range from 9 through 26 years to 9 through 45 years for both women and men (Meites, 2019).

Low HPV vaccine completion (13 to 32%) has been observed in adult sexual minority people (Agenor, Peitzmeier, et al., 2016; McRee et al., 2014; Reiter et al., 2015; Williams et al., 2017). Studies have identified lack of knowledge or trust in vaccines, non-disclosure of sexual identity to providers, and fear of discrimination/stigma as barriers to vaccination in sexual minority people (Barefoot et al., 2017; Cummings et al., 2015; Gerend, Madkins, Phillips, Mustanski, et al., 2016; McRee et al., 2014; Youatt, 2017). The true proportion of adult TGNB

and cisgender sexual minority people who have not received any doses of HPV vaccine is likely higher than the general population given studies to-date (Agenor, McCauley, et al., 2016; Agenor et al., 2015; Agenor, Peitzmeier, et al., 2016; Charlton et al., 2017; McRee et al., 2014; Reiter et al., 2015). There have been few studies that focus on HPV vaccination among TGNB people that similarly demonstrate low vaccine uptake (Bednarczyk et al., 2017; Singh et al., 2019).

Methods

We adapted the Integrative Model of eHealth Use or IMeHU (Bodie & Dutta, 2008) to guide our study. The IMeHU posits that online health information seeking is associated with health behavior outcomes and that this relationship is influenced by individual factors such as eHealth literacy (Figure 5.1). We employed a cross-sectional study design to explore the association of health information seeking and eHealth literacy and HPV vaccination among SGM people. Between February and May 2020, we launched an online survey to explore our study questions. An e-mail and text message invitation to participate in the survey was sent to over 17,000 current participants in The Population Research in Identities and Disparities for Equality (PRIDE) Study (pridestudy.org), a large-scale long-term U.S.-based national health study of SGM people (The PRIDE Study, 2019). The PRIDE Study launched in 2017 and recruits only adults age 18-years and older. Details of The PRIDE Study longitudinal cohort and dataset are described elsewhere (Lunn, Capriotti, et al., 2019; Lunn, Lubensky, et al., 2019). This study was approved by the Institutional Review Boards at Columbia Irving University Medical Center (IRB-AAAS6733) and Stanford University Medical School.

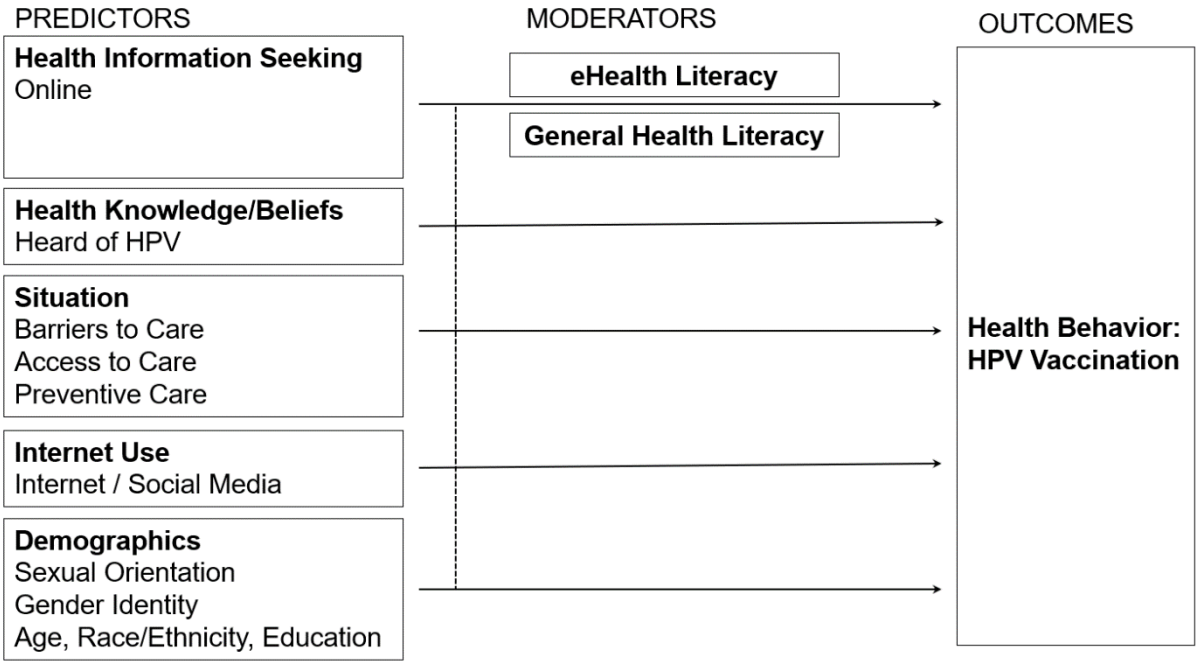

Figure 5. 1 Adapted Integrative Model of eHealth Use (IMeHU)

All participants in The PRIDE Study cohort were deemed eligible for the online survey with no age restrictions and no restrictions to participant sexual or gender identity demographic information. Survey data were collected using Qualtrics (Qualtrics, Provo, UT) and the survey was hosted on The PRIDE Study Web portal. We used a modified Dillman method for survey reminders that were issued by The PRIDE Study Web portal via email and opt-in text message (Dillman et al., 2014).

We used 23-items from the Health Information National Trends Survey (HINTS 5 Cycle 3) (Appendix D) to assess preferences for online health information seeking (National Cancer Institute, 2018). By using HINTS items, we sought to better understand preferences for information seeking, especially among TGNB people as these communities were omitted in previous versions of HINTS. We assessed the health information seeking primary independent variables of interest using two HINTS items:

HINTS_B3) In the **PAST 12 MONTHS,** have you used the Internet to look for information about vaccines for yourself?

HINTS_B5a) In the **PAST 12 MONTHS**, have you used a computer, smartphone, or other electronic means to do any of the following? Looked for health or medical information for yourself.

We assessed eHealth literacy using the electronic Health Literacy Scale (eHEALS), an eight-item scale that uses Likert responses and yields a score 8-40 (low-to-high), corresponding with self-perceived eHealth literacy (Appendix B) (Norman & Skinner, 2006). We assessed general health literacy using three discrete subjective items that address reading and understanding written health information (*e.g.*, confidence in filling out forms, difficulty understanding written communication, and needing help to read written material from a doctor/pharmacy). These items were also constructed with Likert responses (Chew et al., 2004).

We assessed barriers to care, access to care and preventive care, and demographic characteristics, and whether participants had ever received HPV vaccine and number of doses received using items taken from the PRIDE Study annual follow-up questionnaire that is sent annually during the month of June. Although these items were previously posed to participants, the questions were posed again to ensure the completeness of our cross-sectional survey. The final survey included 74 items (Appendix E) and could be completed in 15-20 minutes. The survey item categories and number of items in each category were distributed as follows: HPV and vaccine knowledge (3-items), health information seeking (23-items), general health literacy (3-items), eHealth literacy (10-items), barriers to care (5-items), access to care (7-items), preventive care (8-items), and demographics (15-items). Survey responses from TGNB participants were compared with cisgender sexual minority participants as the reference group.

Participants could skip any item and start and stop the survey as much as they liked during the survey period by logging into their existing PRIDE Study Web portal accounts.

Comparison Groups

We used the responses from multiple demographic questions (*e.g.*, gender identity, lived gender day-to-day, assigned sex at birth, organs born with, organs now) to identify TGNB participants and distinguish them from cisgender participants. We used Boolean logic to account for both gender identity and biological sex. Table 5.1 summarizes the comparison groups and our inclusion logic.

Statistical Analysis

The dataset was cleaned and all analysis performed in SAS 9.4 (SAS Institute Inc., Cary, NC). Descriptive statistics for demographics were calculated and means and standard deviations established. Chi-square and paired t-tests were employed to examine differences in categorical and continuous variables. Alpha was set at .001 for level of significance for bivariate comparisons to control for multiple comparisons. The distribution of continuous variables and potential outlier values for age and eHEALS scores were identified using boxplots in SAS. To determine if multicollinearity was present, we used variance inflation factor (VIF) statistics. A VIF value less than five suggested no multicollinearity (Akinwande et al., 2015). We calculated point prevalence for receipt of HPV vaccine ever, vaccine initiation (*e.g.*, 1-dose) vaccine completion (*e.g.*, 3-doses). We calculated prevalence ratios (PR) and confidence intervals (CI) using robust Poisson statistics (Petersen & Deddens, 2008). We used multivariable logistic regression to model the association of health information seeking on the dependent vaccination outcomes. The prevalences of receipt of HPV vaccination ever, vaccine initiation, and vaccine completion were stratified by gender identity, sex organs born with, sex organs now, and sex

assigned at birth. The multivariable logistic regression was conducted for all TGNB compared to all cisgender participants for the three dependent outcomes (*i.e.*, receipt of HPV vaccination ever, vaccination initiation, and vaccination completion). We performed post hoc testing using the Bonferroni-Holm sequential procedure for adjusted alphas (Eichstaedt et al., 2013). To test for any moderating effects, we assessed for interaction between general and eHealth literacy online health information seeking. For each dependent outcome, we ran two models adding in the interaction terms, eHEALS score and each of the categorical general health literacy variables one at a time. We evaluated the effect of the interaction variables on the logistic regression models using Likelihood Ratio tests.

Results

At the close of the survey, there were 3,339 completed responses (*e.g.*, viewed every question and arrived at survey completion page), and a response rate of 19.6%. We excluded 81 (2.4%) of the responses due to missing sex and gender identity or age information. Of the remaining 3,258 participants, a total of 1,172 (36%) were classified as TGNB and 2,086 (64%) as cisgender (Table 5.2). A greater proportion of TGNB participants were assigned female at birth (AFAB) (79.4%) compared to cisgender AFAB (56.1%) ($p < .0001$). Conversely, the proportion of TGNB participants who were assigned male at birth (AMAB) (20.6%) was half that of cisgender AMAB participants (43.9%) ($p < .0001$). One-third of TGNB participants (35.8%) said their lived gender day-to-day was sometimes man/woman or a third gender or something other than a man or woman. The proportion of cisgender participants that identified as gay sexual orientation was over twice (44.6%) that of TGNB participants (15.9%) ($p < .0001$). Over half (57.3%) of TGNB participants identified as queer sexual orientation compared to cisgender participants (29.6%) ($p < .0001$). The majority of TGNB and participants were White

(81.6%) and had more than a high school education (93.7%) (Table5.2). Cisgender participants were also majority White (82.5%) and nearly all (96.6%) had more than a high school education. TGNB participants reported lower annual income than cisgender participants with more than three-quarters of TGNB participants (76.7%) with an income less than $50,000 per year compared to cisgender participants (55.1%) ($p < .0001$). Slightly more TGNB participants rated their health as fair/poor (43%) compared with cisgender (40.1%) ($p < .0001$). The median age of participants was 31 (interquartile range [IQR] 25-43). Cisgender participants were slightly older than TGNB participants, age mean 38.2 *SD* 14.9 and age mean 31.7 *SD* 11.6 respectively ($p < .0001$).

Barriers to Care, Access to Care, Preventive Care

Over forty-three percent of TGNB participants (43.3%) delayed necessary medical care in the past year compared to cisgender (24.5%) ($p < .0001$). Nearly one-third of TGNB participants reported not seeing a health care provider because they thought they would be disrespected or mistreated in the past year compared to one-tenth of cisgender participants (9.9%) ($p < .0001$). In terms of access to care, majority of both groups reported having a primary care provider (PCP), seeing them in the past year. Nearly all participants reported having health insurance. With regards to preventive care, nearly all TGNB and cisgender participants reported having received a vaccine other than HPV and majority of both groups had received three-or-more vaccines since 18-years age.

Health Literacy

Both groups reported a high level of eHealth literacy with similar eHEALS scores (range 8-40); TGNB participants score mean 32.9 *SD* 4.8 and cisgender participants score mean 33.9 *SD* 4.8 ($p < .0001$). The groups were also similar in how they rated their general health literacy

with majority of participants in either group reporting high confidence filling out forms, and occasional/never difficulty understanding written communication or needing help to read written material from a doctor or pharmacy.

Health Information Seeking

The groups were similar in terms of health information seeking (Table 5.3). Majority of both groups indicated they would use the Internet first when looking for health information and next a doctor or health care provider. Nearly all reported using a computer, smartphone or other electronic means to look for health or medical information in the past year. The groups did not differ in terms of having a smartphone and did not differ in terms of Internet use such as visiting social media sites like Facebook or watching a health-related videos on YouTube or other streaming services.

HPV Vaccination Rates

More TGNB participants (55.8%) reported ever receiving HPV vaccine compared to cisgender (41.9%) ($p < .0001$) (Table 5.4). Of the participants who reported receiving HPV vaccine ever, the groups were similar in number of doses received with a greater proportion of cisgender participants reporting receipt of 3-doses (69.1%) compared to TGNB participants (61.3%) ($p = .0009$). Nearly all had heard of HPV (Table 5.5). Small proportions of TGNB participants (2.8%) and cisgender participants (3.7%) reported that a doctor refused to give them HPV vaccine when they requested it ($p = .0009$).

The prevalence (PR 1.3; 95% CI, 1.3-1.4) of ever receiving HPV vaccine was 1.3 times greater among TGNB participants than cisgender participants (Table 5.6). However, of the aggregate TGNB and cisgender participants who reported ever receiving an HPV vaccine, there was no difference in vaccine initiation (*e.g*, received 1-dose) or vaccine completion (*e.g.*,

received 3-doses). There were notable differences when comparing groups based on gender identity and sex organs born with. TGNB identity and organs born female had 1.2 times prevalence (PR 1.2; 95% CI, 1.1-1.2) of ever receiving HPV vaccine compared to cisgender females. However, they were 0.9 times as likely (PR 0.9; 95% CI, 0.8-0.9) complete 3-doses of vaccine. When considering gender identity, organs now and sex assigned at birth, the groups with the greatest difference in vaccination prevalence was TGNB participants with organs now male and AMAB whose prevalence (PR 3.2; 95% CI, 1.2-9.1) of vaccination initiation was 3.2 times greater than cisgender participants with male organs now and AMAB. There was no difference in prevalence of vaccination among TGNB participants who were categorized as transmasculine (e.g., self-identified as a man or transgender man) and transfeminine. However, transgender nonbinary AFAB had 1.6 times prevalence (PR 1.6; 95% CI, 1.3-2.0) of ever receiving HPV vaccine compared to nonbinary AMAB. Nonbinary transgender participants had 1.2 times the prevalence of ever receiving HPV vaccine compared to binary transgender participants (*e.g.*, transgender people who identified as transmasculine or transfeminine). The prevalence (PR 4.6; 95% CI, 1.1-19.1) of vaccine initiation was 4.6 times higher in participants who were born with male organs and now have female organs compared to participants who were born with male organs and now have male organs. However, the large effect size is likely over-estimated given the small number (n=2) of participants who were born with male organs and now have female organs.

Dependent Outcomes: HPV Vaccination Ever, HPV initiation, HPV completion

To explore the relationship between health information seeking and each dependent outcome of interest, we performed multivariable logistic regression. In our sample of 3,258 participants 1,528 (46.9%) people had ever received any HPV vaccine doses. First, we performed a bivariate analysis of 30 independent variables on each of the three dependent outcomes (*i.e.*, HPV vaccine ever, HPV initiation, HPV completion). Variables that did not meet our entry criterion of $p < .25$ and were removed and not proposed in the preliminary main effects model. Independent variables of interest were selected based on the IMeHU categories (e.g., gender identity, health information seeking, knowledge/beliefs, Internet use, barriers to care, access to care, preventive care, demographics). We include the detailed bivariate analysis including Chi-square values for the dependent outcome receipt of HPV vaccine ever (Table 5.7) but do not display the detailed Chi-square distribution for the other two dependent variables (e.g. vaccine initiation / completion). We include a summary of the bivariate analysis, preliminary main effects model, and final reduced model are for each of the three dependent outcomes (Tables 5.8-5.10). Of note, some variables were kept in the model even though they did not meet the entry or retain alpha criteria because they were main factors under investigation and as such important variables of interest (*e.g.*, gender identity and/or online information seeking).

Dependent Outcome: HPV Vaccine Ever

After controlling for covariates including age, race/ethnicity and education attainment, we found that TGNB participants had increased odds (aOR=1.5=; 95% CI, 1.1-2.2) of reporting receipt of HPV vaccine ever compared to cisgender participants (Table 5.8). TGNB participants compared to cisgender participants had decreased odds (aOR=0.7; 95% CI, 0.5-0.9) of receipt of HPV vaccine when they looked for info on vaccines in the past year. TGNB participants had

over twice the odds (aOR=2.4; 95% CI, 1.1-5.6) of ever receiving HPV vaccine if they visited a social networking site like Facebook in the past year; and also had over twice the odds (aOR=2.1; 1.1-4.1) of ever receiving vaccine if they reported having heard of HPV. TGNB participants had 1.5 odds (aOR=1.5; 95% CI, 1.1-2.0) of receiving HPV vaccine ever compared to cisgender participants when they reported having delayed medical care in the past year. Having less than 50% of health care providers be aware of sexual orientation or gender identity was significant in preliminary modeling but ultimately not associated with the HPV vaccine receipt in the reduced model. TGNB participants had decreased odds of ever receiving HPV vaccine compared to cisgender participants if they reported tracking healthcare charges and costs (aOR=0.6; 95% CI, 0.5-0.9), or if they reported have made appointments with their providers online (aOR=0.5, 95% CI, 0.4-0.9). Medicaid was also associated with decreased odds of ever receiving HPV vaccination (aOR=0.3; 95% CI 0.1-0.7). In terms of preventive care, TGNB participants compared to cisgender participants had two times the odds (aOR=2.0; 95% CI, 1.5-2.8) of ever receiving HPV vaccine when they reported having had an HIV test in the past year. The greatest effect size was observed when participants reported receipt of vaccines other than HPV, TGNB participants who reported receipt three-or-more vaccines since they were 18-years old had 3.5 times the odds (aOR=3.5; 95% CI, 1.5-8.2) of ever receiving HPV vaccine compared to cisgender participants. TGNB participants who reported having had any anorectal cancer screening had decreased odds (aOR=0.6; 0.4-0.8) of receiving vaccine ever compared to cisgender participants. In terms of covariates, TGNC participants who were age younger than 27-years decreased odds (aOR=0.08; 95% CI, 0.05-0.11) of receiving HPV vaccine ever compared to cisgender participants younger than 27-years age. However, the remaining covariates race and education attainment were not significant in the reduced model.

Dependent Outcome: HPV Vaccine Initiation (1-dose)

Of the individuals who reported HPV vaccine ever (*N*=1,528) we performed logistic regression modeling on vaccine initiation (*e.g.*, received 1-dose). After bivariate analysis (Table 5.8) we proposed a preliminary main effects model. Most of the independent variables were ultimately removed from the reduced model, failing to meet the $p<.05$ retain criteria. In the final reduced model, we found no association between TGNB identity and vaccine initiation. However, we did find an association with health information seeking, number of vaccines other than HPV received, and age. Looking for vaccine info online in the past year was associated with 2.7 times the odds of vaccine receipt (aOR=2.7; 95% CI, 1.8-4.1). Receipt of three-or-more vaccines other than HPV was associated with decreased odds (aOR=0.3; 0.1-0.9) of vaccine initiation. In terms of covariates, Age <27-years was associated with 1.8 times the odds (aOR=1.8; 95% CI, 1.2-2.8) of vaccination initiation. The other two covariates, race/ethnicity and education attainment were not significant in the reduced model.

Dependent Outcome: HPV Vaccination Completion (3-doses)

We re-ran the bivariate analysis for the dependent outcome vaccine completion or receipt of 3-doses of HPV vaccine (Table 5.10). After proposing a preliminary model, the reduced model retained eight independent variables at the $p<.05$ level. After controlling for covariates age, race/ethnicity and education attainment, TGNB participants had decreased odds (aOR=0.7; 95% CI, 0.5-0.9) of vaccine completion compared to cisgender participants. TGNB participants that looking for any health information online had nearly four times the odds (aOR=3.8; 95% CI, 1.4-10.5) of vaccine completion compared to cisgender participants but there was no association with vaccine completion if they searched for information about vaccines online in the past year (aOR=0.7; 95% CI, 0.6-1.0). TGNB participants had decreased odds (aOR=0.5; 95% CI, 0.3-0.8)

of vaccine completion if they saw their PCP in the last year. TGNB participants had nearly five times the odds (aOR=4.8; 95% CI, 1.9-12.2) of vaccine completion if they reported having received one-to-two vaccines since 18-years old and nearly seven times the odds (aOR=6.7; 95% CI, 2.8-16.1) of vaccine completion if they received three-or-more vaccines since age 18-years. In terms of covariates, age, race/ethnicity and education attainment were not significant in the reduced model.

Interaction of Health Literacy

To test for the moderating effect, we assessed for interaction between online health inforamation seeking and eHealth/general health literacy. After adding interaction terms for the eHEALS score and each of the general health literacy variables to the three reduced logistic regression models, we found no interaction between general and eHealth literacy and online health information seeking using the LR method.

Discussion

Our study found that in a sample of 3,258 SGM people participating in a large national online cohort, 1,528 (46.9%) people received the HPV vaccine (ever) and of the people who received the HPV vaccine ever, 121 (7.9%) received 1-dose and 1,004 received 3-doses (65.7%). In general, TGNB people were more likely to have ever received HPV vaccine. Our finding that TGNB participants with female organs were more like to ever receive vaccination and complete 3-dose vaccination series compared to cisgender participants with female organs is worth consideration. Both TGNB and cisgender sexual minority people have been known to delay or not receive necessary care and TGNB people may experience increased rates of discrimination in healthcare (Jaffee et al., 2016; Macapagal et al., 2016). Higher receipt of HPV vaccine among TGNB people compared to cisgender sexual minority people in our sample may be related to

how they engage with health care. Both groups reported having a PCP and saw them in the last year and over half TGNB people also reported going to a provider/clinic for transgender care in the past year. Increased engagement in healthcare for gender affirmation may increase their contact with primary care providers who would suggest vaccination (Edmiston et al., 2016). Moreover, majority of both groups reported receiving three of more vaccines other than HPV since 18-years age, this likely reflects high primary care engagement in our sample.

Our findings that individuals who are born with female organs born have increased rates of HPV vaccination regardless of gender identity is consistent with what is known in the literature about HPV vaccination in sexual minority people such as gay men who have been shown to have vaccination initiation rates as low as 13% compared to 47% in studies of sexual minority women (Agenor, Peitzmeier, et al., 2016; Reiter et al., 2015). A study of rural residing LGBT people found that on the basis of sex assigned at birth HPV vaccine initiation was 42% for females and 14% for males (Bednarczyk et al., 2017). Vaccination rates have not been described with large samples of TGNB people. To our knowledge this is the first study to describe HPV vaccination rates in a larger national sample of TGNB people.

Because ACIP guidelines recommended that only girls to be vaccinated when the vaccine was first introduced and boys were added 3 years later, this gender-based lag in policy likely decreased uptake in boys which is further compounded with decreased knowledge that the vaccine is recommended for all. In our sample, most of the participants had heard of HPV. However, studies have shown that SGM people have knowledge deficits regarding HPV infection and prevention and the common misconception among sexual minority people and transgender people alike is that HPV vaccination is only for women or people with female sex organs (Apaydin, Fontenot, Shtasel, et al., 2018).

Eight months prior to the launch of our survey, ACIP still recommended a maximum age of 26 years for receiving the HPV vaccine and it should be noted that ACIP explicitly added transgender people to its recommendation for HPV vaccination for the first time in December 2016 (Meites, 2019). We performed a sub-analysis of this group and found that they were not at increased odds of receipt of vaccination compared to the rest of the sample. We also controlled for age in our logistic regression model and found that age less than 27-years old decreased odds of vaccination ever and increased odds of vaccine initiation but had no effect on vaccine completion among TGNB people compared with cisgender sexual minority people. There may also be individuals who received the HPV vaccine who are older than the recommendation. Special populations deemed at higher risk of HPV-infection and HPV-associated cancer may receive HPV vaccines through shared decision-making with their health care providers like people living with HIV and others (Lacey, 2019).

Our logistic regression modeling showed decreased odds of ever receiving HPV vaccine when they searched for information about vaccines in the past year. This is a curious finding with multiple possible explanations. This may reflect concerns about the safety or necessity of vaccines that is manifested as vaccine hesitancy (Siddiqui et al., 2013). It is possible that the individuals that searched for vaccine information are more likely to have vaccine hesitancy. It is also possible that the quality of information that individuals encounter when searching for health information in general in contrast to vaccine-specific information could affect personal health decision-making and receipt of HPV vaccine, especially if the quality of the vaccine information is poor or increases anxiety through misinformation. Anti-vaccine Web content, even some specific to HPV vaccine have proliferated in recent years and research has shown that pro-HPV vaccine online videos on YouTube were 4 times more likely to report accurate information than

anti-vaccine videos (Ekram et al., 2019). Conversely, our finding that visiting social networking sites like Facebook increased the odds of ever receiving vaccine for TGNB participants is notable given the ubiquity and widespread use of social media today. Peer norms have been found to be a facilitator for preventative vaccination in sexual minority people and this could have implications for vaccination information sharing through social media platforms that have growing use among TGNB and SGM communities more broadly (Dahlhamer et al., 2017).

There have been a limited number of studies that investigate the association of health information seeking and vaccination in sexual minority people. A study of men who have sex with men (MSM) showed an increase in receipt of HPV vaccine in those who searched online for sexual health (Stupiansky et al., 2017). Additional research found that MSM had higher perceived benefits of vaccination when they had higher levels of health information orientation (Wheldon, Daley, et al., 2018). These findings suggest that online health information seeking may represent an avenue for interventions to address HPV vaccine uptake among SGM communities. Moreover, an association between health information seeking and vaccination is further supported by recent findings that individuals who encounter cultural barriers to access care are more likely to seek health information online (Perez et al., 2016).

Having heard of HPV increased the odds of ever receiving a vaccine which is consistent with the literature that has examined knowledge of HPV and vaccination among SGM communities (Apaydin, Fontenot, Shtasel, et al., 2018; Gerend, Madkins, Phillips, & Mustanski, 2016; McRee et al., 2014). The decreased odds of ever receiving vaccine observed when TGNB people tracked healthcare charges/costs electronically or made appointments with health care providers online are Internet use behaviors would benefit from further investigation. Out-of-pocket costs for care may be a perceived barrier to individuals who track costs closely. Research

has shown that cost of other vaccines is a barrier in sexual minority people (Wheldon et al., 2017). This would especially be true with lower income individuals who have Medicaid which is consistent with our findings of decreased odds of ever receiving HPV vaccine when TGNB participants had reported having Medicaid compared to cisgender participants. The association of decreased vaccine receipt and online appointment making may be associated with a perceived barrier to obtaining care if preventative care appointments are not readily available. Having had an HIV test in the past year was associated with increase in ever receiving vaccination, which is also consistent with studies that have shown an increase in preventative vaccination in sexual minority people when HIV and STI testing was bundled together with vaccination (Cummings et al., 2015; Fontenot et al., 2016; Gorbach et al., 2017).

Comparing TGNB participants and cisgender participants, there were conflicting results in vaccine initiation and vaccine completion. Having looked for information on vaccines in the past year was associated with an increase in vaccine initiation but not associated with vaccine completion. This could possibly be explained by the timing of online searching for vaccine information. Individuals that search for vaccine information before they initiate the HPV vaccine series may have increased intention to receive the HPV vaccine. However, searching for vaccine information may not have been associated with HPV series completion because the information received was more critical to the decision to start the series versus continuing to receive it. Conversely, searching for general health information was associated with vaccine completion but not vaccine initiation which might suggest that the type of information that is received from general health information online reinforces the need to complete the HPV vaccine series, or that TGNB individuals who regularly search for health information online are more likely to be engaged in their care. Having received three-or-more vaccines other than HPV was associated

with increased odds of vaccine completion but decreased vaccine initiation among TGNB participants compared to cisgender participants. This difference might be reconciled by closer examination primary care engagement. On the one hand an individual that received three-or-more vaccines other than HPV may be highly engaged in their care and reminded to complete all doses. However, they might also experience confusion in the dosing schedule if they are also receiving other multi-dose vaccinations like hepatitis A/B. Moreover, concerns about multiple doses as a barrier to vaccination have been expressed by SGM people in qualitative studies exploring HPV vaccination (Apaydin, Fontenot, Shtasel, et al., 2018). Finally, being age 27-years or younger was associated with an increase in vaccine initiation and a decrease in vaccine completion. It is possible that this is related to parent/caregiver deciding to initiate the vaccine for an adolescent but difficulty following-through to the second and third dose of the series, possibly also from confusion about the schedule, simply forgetting the need to return for additional doses, or are in the middle of completing the vaccine series. More study is warranted.

The greatest effect sizes for increased odds of ever receiving HPV vaccine were observed if an individual received three-or-more vaccines other than HPV since they were 18-years old. This is consistent with the literature that has demonstrated that when services like HIV testing, or other vaccines such as hepatitis A/B are bundled together it can increase vaccine uptake among SGM communities (Apaydin, Fontenot, Borba, et al., 2018).

Although we found no moderating effects of eHealth literacy or general health literacy, this is consistent with the high health literacy sample that had generally high eHEALS scores and reported little challenges understanding health information. It is likely that the lack of variability in health literacy further limited any moderating effects.

Strengths/Limitations

This study has several strengths. It is the first study to investigate HPV vaccination in a large national sample of TGNB people. It leverages an online national cohort of SGM people are being followed longitudinally. It is the first study to describe health information seeking and health literacy among TGNB people using items from validated instruments and survey items. However, the study is not without its limitations. The logistic regression model we investigated was informed by theory which was helpful in proposing independent variables of interest. The PRIDE Study is a convenience sample and given majority of participants were white and had greater than a high school education, our sample is not necessarily representative of TGNB and cisgender sexual minority people. Moreover, our primary dependent outcomes receipt of HPV vaccination and number of doses received is subject to recall bias which may worsen over time. Finally, the cross-sectional nature of the study limits our ability to derive any causal relationships.

Conclusion

In summary, in our cross-sectional study of online health information seeking and HPV vaccination, we found TGNB people had higher prevalence of receipt of HPV vaccine ever compared with cisgender sexual minority people. TGNB people who were born with female organs or were assigned female at birth, or female sex organs now also reported higher prevalence of receipt of vaccine ever and receipt of vaccine completion but not vaccine initiation regardless of their current gender identity. These findings suggest disparities in HPV vaccine receipt among SGM that mirror the general population with a bias towards people born with female organs. We also found seeking online information about vaccines was associated with a decreased in receipt of HPV vaccine ever, was associated with vaccine initiation, and but not

associated with vaccine completion among TGNB people compared with cisgender sexual minority people. We also found that seeking general health information in the past year was associated with an increase in vaccine completion but not vaccine initiation or ever receiving HPV vaccine. Factors most associated with HPV receipt were having received three-or-more vaccines since 18-years old, having heard of HPV, and having visited a social networking site like Facebook. We found no moderating effects of general or eHealth literacy. Future studies should focus on further exploration of preferences for online health information seeking and online social media use as a potential to develop interventions for TGNB and cisgender sexual minority people, especially those born with male sex organs to potentially improve the uptake of HPV and other vaccines, especially those that require multiple doses over time.

Table 5. 1 Comparison groups

Comparison	Group	Reference
A1. TGNB all compared to: Cisgender all	TGNB (ALL) Administrative identification / stratified by gender identity (A2 ALL and A3 ALL)	CISGENDER (ALL) Administrative identification / stratified by gender identity (A2 ALL and A3 ALL)
A2. Transgender men compared to: Transgender women	Transgender Man SAAB (Female2) AND GENDERID (Genderqueer1 OR Transgender man3 OR Man2 OR Another gender identity6)	Transgender Woman SAAB (Male1) AND GENDERID (Genderqueer1 OR Transgender woman4 OR Woman5 OR Another gender identity6)
A3. Cisgender female compared to: Cisgender male	Cisgender Female SAAB (Female2) AND GENDERID (Woman5)	Cisgender Male SAAB (Male1) AND GENDERID (Man2)
B1. TGNB organs born female compared to: Cisgender female	GENDERID (Genderqueer1 OR Transgender man3 OR Transgender woman4 OR Man2 OR Another gender identity6) AND ORGANS_BORN (cervix1 OR ovaries2 OR uterus OR vagina7)	GENDERID (Woman5) AND ORGANS_BORN (cervix1 OR ovaries2 OR uterus6 OR vagina7)
B2. TGNB organs born male compared to: Cisgender male	GENDERID (Genderqueer1 OR Transgender man3 OR Transgender woman4 OR Woman5 OR Another gender identity6) AND ORGANS_BORN (penis3 OR prostate4 OR testicles5)	GENDERID (Man2) AND ORGANS_BORN (penis3 OR prostate4 OR testicles5)
C1. Organs born male + organs now female compared to: Organs born male + organs now male	ORGANS_BORN (penis3 OR prostate4 OR testicles5) AND ORGANS_NOW (vagina8)	ORGANS_BORN (cervix1 OR ovaries2 OR uterus6 OR vagina7) AND ORGANS_NOW (cervix2 OR ovaries3 OR uterus7, vagina8)
C2. Organs born female + organs now male compared to: Organs born male + organs now male	ORGANS_BORN (cervix1 OR ovaries2 OR uterus6 OR vagina7) AND ORGANS_NOW (penis4 OR testicles6)	ORGANS_BORN (penis3 OR prostate4 OR testicles5) AND ORGANS_NOW (penis4 OR prostate5 OR testicles6)
D1. TGNB + Organs Now Female + AFAB compared to: Cisgender + Organs now female +AFAB	GENDERID (Genderqueer1 OR Transgender Man3 OR Transgender Woman4 OR Another gender identity6) AND ORGANS_NOW (cervix2 OR ovaries3 OR uterus7 OR vagina8) AND SAAB (Female2)	GENDERID (Woman5) AND ORGANSNOW (cervix2 OR ovaries3 OR uterus7 OR vagina8) AND SAAB (Female2)

Comparison	Group	Reference
D2. TGNB + Organs Now + Assigned Male at Birth (AMAB) compared to:	GENDERID (Genderqueer1 OR Transgender Man3 OR Transgender Woman4 OR Another gender identity6) AND ORGANS_NOW (vagina8) AND SAAB (Male1)	GENDERID (Man2) AND ORGANS_NOW (penis4 OR prostate5 OR testicles6) AND SAAB (Male1)
E1. Binary Identity Transmasculine ALL compared to: Transfeminine ALL	GENDERID (Genderqueer1 OR Transgender Man3 OR Another gender identity6) AND LIVEGEN (Man1) OR GENDERID (Man3) AND SAAB (Female2) AND LIVEGEN (Man1)	GENDERID (Genderqueer1 OR Transgender Man3 OR Another Gender Identity6) AND LIVEGEN (Woman2) OR GENDERID (Woman5) AND SAAB (Male1) AND LIVEGEN (Woman2)
F1. Nonbinary Identity Nonbinary + AFAB compared to: Nonbinary + AMAB	GENDERID (Genderqueer1 OR Another Gender Identity6) OR LIVEGEN (Sometimes man / sometimes woman3 OR Third gender other than man or woman4) AND SAAB (Female2)	GENDERID (Genderqueer1 OR Another Gender Identity6) OR LIVEGEN (Sometimes man / sometimes woman3 OR Third gender other than man or woman4) AND SAAB (Male1)
F2. Transgender Nonbinary ALL compared to: Transgender Binary ALL	(F1 ALL)	(E1 ALL)

AFAB (Assigned Female at Birth)
AMAB (Assigned Male at Birth)
SAAB (Sex Assigned at Birth)
TGNB (Transgender and Gender Nonbinary)

Table 5. 2 Participant characteristics

(*N*=3,258)		Total		TGNB ALL		CISGENDER ALL		
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	***X*²**	***p*-value**
DEMOGRAPHIC								
Sexual Orientation								
Asexual	353	(10.8)	225	(19.2)	128	(6.1)	132.5	<.0001
Bisexual	941	(28.9)	382	(32.6)	559	(26.8)	12.3	<.0005
Gay	1,117	(34.2)	186	(15.9)	931	(44.6)	25.5	<.0001
Lesbian	698	(21.4)	173	(14.8)	525	(25.2)	48.3	<.0001
Pansexual	454	(13.9)	256	(21.8)	198	(9.5)	95.5	<.0001
Queer	1,289	(39.6)	672	(57.3)	617	(29.6)	241.8	<.0001
Questioning	67	(2.1)	37	(3.2)	30	(1.4)	-	.0005*
Same-gender loving	150	(4.6)	71	(6.1)	79	(3.8)	8.8	.0030
Straight/Heterosexual	60	(1.8)	47	(4.0)	13	(0.6)	-	<.0001*
Two-spirit	18	(0.6)	13	(1.1)	5	(0.2)	-	.0022*
Another sexual orientation	87	(2.7)	57	(4.9)	30	(1.4)	33.9	<.0001
Gender Identity								
Genderqueer	599	(18.4)	487	(41.6)	112	(5.4)	654.8	<.0001
Man	1,091	(33.5)	175	(14.9)	916	(43.9)	283.0	<.0001
Transgender man	410	(12.6)	407	(34.7)	3	(0.1)	815.8	<.0001
Transgender woman	165	(5.1)	164	(14.0)	1	(0.1)	303.5	<.0001
Woman	1,247	(38.3)	75	(6.4)	1,172	(56.2)	787.2	<.0001
Another gender identity	408	(12.5)	361	(30.8)	47	(2.3)	558.3	<.0001
Lived gender day-to-day (missing=4)								
Man	1329	(40.8)	415	(35.5)	914	(43.8)	818.1	<.0001
Woman	1491	(45.8)	335	(28.7)	1156	(55.4)		
Sometimes man/woman*	66	(2)	62	(5.3)	4	(0.2)		
Third gender or something other than man or woman	368	(11.3)	356	(30.5)	12	(0.6)		
Assigned sex at birth								
Male	1,156	(35.5)	241	(20.6)	915	(43.9)	178.0	<.0001
Female	2,102	(64.5)	931	(79.4)	1,171	(56.1)		
Organs born with								
Cervix	2,104	(64.6)	936	(79.9)	1,168	(56.0)	186.9	<.0001
Ovaries	1,933	(59.3)	812	(69.3)	1,121	(53.7)	75.1	<.0001
Penis/Phallus (not prosthetic)	1,942	(59.6)	826	(70.5)	1,116	(53.5)	89.8	<.0001
Prostate	1,135	(34.8)	223	(19.0)	912	(43.7)	201.6	<.0001
Testicles	1,090	(33.5)	215	(18.3)	875	(42.0)	187.8	<.0001

(*N*=3,258)			TGNB		CISGENDER			
		Total		ALL		ALL		
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	X^2	***p*-value**
Uterus/Womb	1,086	(33.3)	185	(15.8)	901	(43.2)	253.7	<.0001
Vagina/Frontal genital opening	1,911	(58.7)	802	(68.4)	1,109	(53.2)	72.1	<.0001
Organs now								
Breasts or breast tissue	1,945	(59.7)	771	(65.8)	1,174	56.3	28.2	<.0001
Cervix	1,933	(59.3)	812	(69.3)	1,121	(53.7)	75.1	<.0001
Penis/Phallus (not prosthetic)	1,952	(59.6)	826	(70.5)	1,116	(53.5)	89.8	<.0001
Prostate	1,135	(34.8)	223	(19.0)	912	(43.7)	201.6	<.0001
Testicles	1,090	(33.5)	215	(18.3)	875	(42.0)	187.8	<.0001
Uterus/Womb	1,086	(33.3)	185	(15.8)	901	(43.2)	253.7	<.0001
Vagina/Frontal genital opening	1,911	(58.7)	802	(68.4)	1,109	(53.2)	72.1	<.0001
Race/ethnicity (missing=1)								
American Indian/Alaska Native	11	(0.3)	6	(0.5)	5	(0.2)	29.2	.0001
Asian	75	(2.3)	24	(2.1)	51	(2.4)		
Black, African American, African	60	(1.8)	12	(1.0)	48	(2.3)		
Hispanic, Latino, Spanish	73	(2.2)	15	(1.3)	58	(2.8)		
Middle Eastern, North African	9	(0.3)	2	(0.2)	7	(0.3)		
Native Hawaiian, Pacific Islander	0	(0)	0	0	0			
White	2,676	(82.1)	955	(81.6)	1,721	(82.5)		
Other (None fully describe me)	41	(1.3)	21	(1.8)	20	(1.0)		
Mixed (>1 race/ethnicity selected)	312	(9.6)	136	(11.6)	176	(8.4)		
In a Relationship (missing=5)								
Yes	2.,066	(63.5)	732	(62.6)	1,334	(64.0)	0.6	.4281
No	1,187	(36.5)	437	(37.4)	750	(36.0)		
Legal marital status (missing=5)								
Married	913	(28.1)	261	(22.3)	652	(31.3)	42.2	<.0001
Legally recognized civil union	4	(0.1)	1	(0.1)	3	(0.1)		
Registered domestic partnership	52	(1.6)	11	(0.9)	41	(2.0)		
Widowed	27	(0.8)	6	(0.5)	21	(1.0)		
Divorced	241	(7.4)	99	(8.5)	142	(6.8)		
Separated	31	(1.0)	15	(1.3)	16	(0.8)		
Single, never married	1,985	(61.0)	776	(66.4)	1,209	(58.0)		
Work in one or more paid jobs?								
Yes	2,430	(74.7)	824	(70.4)	1,606	(77.1)	17.7	<.0001
No	823	(25.3)	346	(29.6)	477	(22.9)		
Occupation								
Employed >=40 hr/wk	1,558	(47.8)	468	(40.0)	1,090	(52.3)	121.0	<.0001

(*N*=3,258)			TGNB		CISGENDER			
		Total		ALL		ALL		
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	X^2	***p*-value**
Employed 1-39 hr/wk	448	(13.8)	198	(16.9)	250	(12.0)		
Temporarily employed	26	(0.8)	9	(0.8)	17	(0.8)		
Self-employed	148	(4.5)	46	(3.9)	102	(4.9)		
Not employed, looking	122	(3.8)	63	(5.4)	59	(2.8)		
Not employed, not looking	41	(1.3)	22	(1.9)	19	(0.9)		
Homemaker	40	(1.2)	20	(1.7)	20	(1.0)		
Student full time	500	(15.4)	212	(18.1)	288	(13.8)		
Student part time	60	(1.8)	32	(2.7)	28	(1.3)		
Disabled, not able to work	151	(4.6)	76	(6.5)	75	(3.6)		
Retired	163	5.0)	25	(2.1)	138	(6.6)		
Income 2019 tax year (missing=71)								
$0	158	(5.0)	83	(7.3)	75	(3.7)	195.4	<.0001
$1 – 10,000	511	(16.0)	266	(23.3)	245	(12.0)		
$10,001 – 20,000	348	(10.9)	157	(13.7)	191	(9.4)		
$20,001 – 30,000	341	(10.7)	141	(12.3)	200	(9.8)		
$30,001 – 40,000	376	(11.8)	138	(12.1)	238	(11.7)		
$40,001 – 50,000	265	(8.3)	92	(8.0)	173	(8.5)		
$50,001 – 60,000	238	(7.5)	67	(5.9)	171	(8.4)		
$60,001 – 70,000	171	(5.4)	40	(3.5)	131	(6.4)		
$70,001 – 80,000	149	(4.7)	38	(3.3)	111	(5.4)		
$80,001 – 90,000	113	(3.6)	26	(2.3)	87	(4.3)		
$90,001 – 100,000	97	(3.0)	21	(1.8)	76	(3.7)		
$100,000+	420	(13.2)	75	(6.6)	345	(16.9)		
Education attainment								
High school or less	145	(4.5)	74	(6.3)	71	(3.4)	14.9	.0001
More than high school	3113	(95.5)	1,098	(93.7)	2,015	(96.6)		
SITUATION – BARRIERS TO CARE								
Less than 50% health care providers aware of your sexual orientation	942	(28.1)	373	(31.8)	569	(27.3)	7.6	.0060
Less than 50% health care providers aware of your gender identity	584	(39.4)	378	(32.5)	206	(64.6)	107.6	<.0001
Delayed medical care in past year (missing=1)	1,019	(31.3)	508	(43.3)	511	(24.5)	123.8	<.0001
Did not see provider because thought would be disrespected / mistreated in past year	574	(17.6)	367	(31.3)	207	(9.9)	236.6	<.0001
SITUATION – ACCESS TO CARE								

(*N*=3,258)			TGNB		CISGENDER			
		Total		ALL		ALL		
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	X^2	***p*-value**
Have PCP (missing=45)	2,709	(84.3)	944	(82.0)	1,765	(85.6)	7.2	.0074
Saw PCP in past year (missing=571)	2,397	(89.2)	848	(91.1)	1,549	(88.2)	5.2	.0224
Went to provider/clinic for transgender care in past year (missing=17)	693	(21.4)	679	(58.4)	14	(0.7)	1477.3	<.0001
Have health insurance (missing=13)	3,103	(95.6)	1,096	(94.2)	2,007	(96.4)	8.3	.0039
Type of health insurance								
Medicaid/Medicare	437	(13.4)	173	(14.8)	264	(12.7)	3.2	.1983
Private Insurance	2,637	(80.9)	930	(79.4)	1,707	(81.8)		
Other	184	(5.7)	69	(5.9)	115	(5.5)		
Ever used hormones or medication for gender affirmation (missing=2)	703	(21.6)	691	(98.3)	12	(0.6)	-	<.0001*
Currently using hormones or medications for gender affirmation (missing=2,555)	642	(91.3)	639	(92.5)	3	(25)	-	<.0001*
SITUATION – PREVENTIVE CARE								
Health in general (PROMIS-1)								
Excellent	342	(10.5)	80	(6.8)	262	(12.6)	93.0	<.0001
Very good	1,271	(39.0)	394	(33.6)	877	(42.0)		
Good	1,084	(33.3)	414	(35.3)	670	(32.1)		
Fair	460	(14.1)	228	(19.5)	232	(11.1)		
Poor	101	(3.1)	56	(4.8)	45	(2.2)		
Had HIV test in past year (missing=50)	1,219	(38.0)	438	(38.2)	781	(37.9)	0.04	.8474
HIV status								
Seronegative	2,923	(89.7)	1,077	(91.9)	1,846	(88.5)	-	<.0001*
Seropositive	129	(4.0)	8	(0.7)	121	(5.8)		
Don't know status	206	(6.3)	87	(7.4)	119	(5.7)		
Ever had a vaccine other than HPV?								
Yes	3,136	(96.3)	1,114	(95.1)	2,022	(96.9)	-	.0072*
No	90	(2.8)	39	(3.3)	51	(2.4)		
Don't know	32	(1.0)	19	(1.6)	13	(0.6)		
Preventive vaccines since 18-years old (missing=122)								
None	82	(2.6)	32	(2.9)	50	(2.5)	25.9	<.0001
1-2 vaccines	287	(9.2)	125	(11.2)	162	(8.0)		
3 or more vaccines	2,531	(80.7)	847	(76.0)	1,684	(83.3)		
Don't know								

(*N*=3,258)			TGNB		CISGENDER			
		Total		ALL		ALL		
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	X^2	***p*-value**
Ever had a cervical Pap?								
Yes	1,675	(51.6)	679	(58.2)	996	(47.9)	154.3	<.0001
No	613	(18.9)	293	(25.1)	320	(15.4)		
NA – don't have a cervix	959	(29.5)	195	(16.7)	764	(36.7)		
HPV test with recent Pap (missing 2,156)								
Yes	909	(82.5)	360	(83.5)	549	(81.8)	0.5	.4665
No	193	(17.5)	71	(16.5)	122	(18.2)		
Ever had anal/rectal cancer screening (DRE, anal Pap, etc.) (missing=99)								
Yes	907	(28.7)	214	(19.0)	693	(34.1)	81.3	<.0001
No	2,252	(71.3)	914	(81.0)	1,338	(65.9)		
INTERNET USE								
See Table 5.3 Health Information Seeking								
HEALTH LITERACY								
How confident are you filling out medical forms by yourself? (missing=17)								
Not at all	14	(0.4)	9	(0.8)	5	(0.2)	86.5	<.0001
A little bit	47	(1.5)	31	(2.7)	16	(0.8)		
Somewhat	260	(8.0)	117	(10.0)	143	(6.9)		
Quite a bit	965	(29.8)	421	(46.1)	544	(26.2)		
Extremely	1,955	(60.3)	588	(50.4)	1,367	(65.9)		
How often have problems difficulty understanding written communication? (missing=15)								
Never	2,330	(71.9)	753	(64.5)	1,577	(76.0)	-	<.0001*
Occasionally	660	(20.4)	285	(24.4)	375	(18.1)		
Sometimes	215	(6.6)	103	(8.8)	112	(5.4)		
Often	34	(1.1)	23	(2.0)	11	(2.0)		
Always	4	(0.1)	4	(0.3)	0	0		
How often need help to read written material from doctor/pharmacy?								
Never	2,840	(87.4)	971	(83.3)	1,869	(89.8)	-	<.0001
Occasionally	311	(9.6)	138	(11.8)	173	(8.3)		
Sometimes	74	(2.3)	39	(3.3)	35	(1.7)		
Often	16	(0.5)	12	(1.0)	4	(0.2)		
Always	7	(0.2)	6	(0.5)	1	(0.1)		

			Total		TGNB ALL	CISGENDER ALL		
	Range	**Mean**	**(*SD*)**	**Mean**	**(*SD*)**	**Mean**	***t*-test**	***p*-value**
eHEALTH LITERACY								
eHEALS Score	8 – 40	33.5	4.8	32.9	4.8	33.9	3256	<.0001
Age[+]	18 – 98	35.9	14.2	31.7	11.6	38.2	14.9	3256	<.0001

*Fishers Exact Test for cells <30

[+]Age Median = 31 (interquartile range [IQR 25-43])

Table 5. 3 Health Information Seeking

N = 3,258		Total		TGNB ALL		CISGENDER ALL			
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	**X^2**	***p*-value**
INFORMATION SEEKING								
Ever looked for health info or medical topics from any source?								
Yes	3,134	(96.2)	1,126	(96.1)	2,008	(96.3)	0.1	.7903
No								
The most recent time looked for health info or medical topics where did you go first?								
Books	17	(0.5)	6	(0.5)	11	(0.6)	8.9	.6315
Brochures	16	(0.5)	5	(0.4)	11	0.6)		
Medical organization	172	(5.5)	6	(5.4)	111	(5.5)		
Family	70	(2.2)	22	(2.0)	48	(2.4)		
Friend/Co-worker	35	(1.1)	18	(1.6)	17	(0.9)		
Doctor or health care provider	305	(9.7)	103	(9.2)	202	(10.1)		
Internet	2,447	(78.1)	891	(79.1)	1,556	(77.5)		
Library	20	(0.6)	7	(0.6)	13	(0.7)		
Magazines	13	(0.4)	3	(0.3)	10	(0.5)		
Newspapers	13	(0.1)	2	(0.2)	11	(0.6)		
Telephone info number	4	(0.1)	1	(0.1)	3	(0.2)		
Complementary, alternative of unconventional practitioner	21	(0.7)	7	(0.6)	14	(0.7)		
The most recent time you look for health info or medical topics, who was it for?								
Myself 1	2323	(74.2)	888	(79.0)	1,435	(71.6)	23.0	<.0001
Someone else 2	383	(12.2)	102	(9.1)	281	(14.0)		
Both myself and someone else 3	423	(13.5)	134	(11.9)	289	(14.4)		
Based on results of your most recent search…								
Took a lot of effort to get info needed								
Strongly agree 1	205	(6.6)	118	(10.5)	87	(4.3)	81.6	<.0001
Somewhat agree 2	1,048	(33.5)	419	(37.2)	629	(31.4)		

N = 3,258			TGNB		CISGENDER			
		Total	ALL		ALL			
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	X^2	***p*-value**
Somewhat disagree 3	1,232	(39.4)	424	(37.7)	808	(40.3)		
Strongly disagree 4	646	(20.6)	164	(14.6)	482	(24.0)		
Felt frustrated during your search for info								
Strongly agree 1	309	(9.9)	166	(14.8)	143	(7.1)	103.2	<.0001
Somewhat agree 2	1,025	(32.7)	430	(38.2)	595	(29.7)		
Somewhat disagree 3	1,026	(32.8)	336	(29.9)	690	(34.4)		
Strongly disagree 4	772	(24.7)	193	(17.2)	579	(28.9)		
How confident that could get advice or info about health topics if needed it								
Completely confident 1	1,010	(31.0)	263	(22.4)	747	(35.8)	85.8	<.0001
Very confident 2	1,244	(38.2)	452	(38.6)	792	(38.0)		
Somewhat confident 3	853	(26.2)	380	(32.4)	473	(22.7)		
A little confident 4	117	(3.6)	58	(5.0)	59	(2.8)		
Not confident at all 5	34	(1.0)	19	(1.6)	15	(0.7)		
In general, how much would you trust info about health or medical topics such as info about vaccines from each of the following…								
Doctor or medical provider								
A lot 1	2,569	(78.9)	853	(72.8)	1,716	(82.3)	-	<.0001*
Some 2	614	(18.9)	280	(23.9)	334	(16.0)		
A little 3	68	(2.1)	37	(3.2)	31	(1.5)		
Not at all 4	7	(0.2)	2	(0.2)	5	(0.2)		
Family or friends								
A lot 1	155	(4.8)	52	(4.4)	103	(4.9)	4.2	.2413
Some 2	1,635	(50.2)	566	(48.3)	1,069	(51.3)		
A little 3	1,270	(39.0)	476	(40.6)	794	(38.1)		
Not at all 4	196	(6.0)	78	(6.7)	118	(5.7)		
Government health agencies								
A lot 1	1,271	(39.1)	388	(33.2)	883	(42.4)	34.7	<.0001
Some 2	1,516	(46.6)	577	(49.3)	939	(45.0)		

N = 3,258				TGNB		CISGENDER			
		Total		ALL		ALL			
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	X^2	***p*-value**
A little 3	394	(12.1)	166	(14.2)	228	(10.9)		
Not at all 4	74	(2.3)	39	(3.3)	35	(1.7)		
Charitable organizations (missing=5)								
A lot 1	248	(7.6)	85	(7.3)	163	(7.8)	27.1	<.0001
Some 2	1,656	(50.9)	530	(45.3)	1,126	(54.0)		
A little 3	1,052	(32.3)	436	(37.3)	616	(29.6)		
Not at all 4	297	(9.1)	118	(10.1)	179	(8.6)		
Religious organizations and leaders (missing=3)								
A lot 1	12	(0.4)	5	(0.4)	7	(0.3)	21.7	<.0001
Some 2	159	(4.9)	33	(2.8)	126	(6.0)		
A little 3	580	(17.8)	190	(16.2)	390	(18.7)		
Not at all 4	2,504	(76.9)	942	(80.5)	1,562	(74.9)		
The Internet								
A lot 1	191	(5.9)	60	(5.1)	131	(6.3)	4.3	.2307
Some 2	1,744	(53.6)	614	(52.4)	1,130	(54.2)		
A little 3	1,202	(36.9)	456	(38.9)	746	(35.8)		
Not at all 4	119	(3.7)	41	(3.5)	78	(3.7)		
If had a strong need for info about health or medical topics like vaccines, where would go first?								
Books	13	(0.4)	5	(0.4)	8	(0.4)	11.1	.3468*
Brochures	6	(0.2)	1	(0.1)	5	(0.2)		
Medical organization	320	(9.8)	125	(10.7)	195	(9.4)		
Family	49	(1.5)	12	(1.0)	37	(1.8)		
Friend/Co-worker	22	(0.7)	8	(0.7)	14	(0.7)		
Doctor or health care provider	815	(25.0)	269	(23.0)	546	(26.2)		
Internet	1,854	(56.9)	688	(58.7)	1,166	(55.9)		
Library	21	(0.6)	10	(0.9)	11	(0.5)		
Magazines	-	-						
Newspapers	2	(0.1)	1	(0.1)	1	(0.1)		
Telephone info number	-							

N = 3,258			TGNB		CISGENDER			
		Total	ALL		ALL			
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	X^2	***p*-value**
Complementary, alternative or unconventional practitioner	10	(0.3)	4	(0.3)	6	(0.3)		
Other	146	(4.5)	49	(4.2)	97	(4.7)		
Looked for info about vaccines from any source	2,265	(69.5)	816	(69.6)	1,449	(69.5)	.0092	.9234
Gone online to access the Internet, WWW or send & receive email	3,249	(99.7)	1,167	(99.6)	2,082	(99.8)	1.5	.2203
When using the Internet, access through…								
Regular dial-up telephone line (missing=13)	15	(0.5)	8	(0.7)	7	(0.3)	2.0	.1592
Broadband such as DSL, cable or FiOS (missing=23)	1,959	(60.6)	637	(55.0)	1,322	(63.7)	23.7	<.0001
Cellular network (i.e., phone, 3G/4G) (missing=20)	3,089	(95.4)	1,127	(96.8)	1,962	(94.6)	8.4	.0038
Wireless network (Wi-Fi) (missing=11)								
Used the Internet to look for info about vaccines for yourself in past 12-months (missing=9)	1,068	(32.9)	366	(31.4)	702	(33.7)	1.9	.1704
How often access the Internet through each…								
Computer at home (missing=10)								
Daily 1	2,313	(71.2)	820	(70.3)	1,493	(71.7)	6.6	.0841
Sometimes 2			299	(25.6)	506	(24.3)		
Never 3			11	(0.9)	36	(1.7)		

N = 3,258		Total		TGNB ALL		CISGENDER ALL			
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	**X^2**	***p*-value**
Not Applicable 4			37	(3.2)	46	(2.2)		
Computer at work (missing=15)								
Daily 1	1,894	(58.4)	585	(50.3)	1,309	(63.0)	50.9	<.0001
Sometimes 2	342	(10.6)	139	(11.9)	203	(9.8)		
Never 3	151	(4.7)	63	(5.4)	88	(4.2)		
Not Applicable 4	856	(26.4)	377	(32.4)	479	(23.0)		
Computer in a public place (library, community center, other) (missing=13)								
Daily 1	53		21	(1.8)	32	(1.5)	28.1	<.0001
Sometimes 2	1,008		428	(36.7)	580	(27.9)		
Never 3	1,892		620	(53.2)	1,272	(61.2)		
Not Applicable 4	292		97	(8.3)	195	(9.4)		
On a mobile device (cell phone / smartphone / tablet) (missing=10)								
Daily 1	3,031	(93.3)	1,098	(94.1)	1,933	(92.9)	6.6	<.0826
Sometimes 2	175	(5.4)	58	(5.0)	117	(5.6)		
Never 3	27	(0.8)	4	(0.3)	23	(1.1)		
Not Applicable 4	15	(0.5)	7	(0.6)	8	(0.4)		
Used a computer, smartphone, or other electronic means in past 12 months to…								
Look for health or medical info for yourself	3,170	(97.3)	1,153	(98.4)	2,017	(96.7)	8.1	.0044
Bought medicine or vitamins online (missing=2)	1,448	(44.5)	492	(42.0)	956	(45.9)	4.6	.0319
Used e-mail or Internet to communicate with a doctor or doctor's office (missing=4)	2,701	(83.0)	1,009	(86.2)	1,692	(81.2)	13.0	.0003
Tracked healthcare charges and costs	2,303	(70.8)	859	(73.5)	1,444	(69.3)	6.6	.0105

N = 3,258		Total		TGNB ALL		CISGENDER ALL			
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	**X^2**	***p*-value**
(missing=6)								
Looked up medical test results (missing=4)	2,560	(78.7)	927	(79.2)	1,633	(78.4)	.3395	.5601
Made appointment with a healthcare provider (missing=3)	2,555	(78.5)	931	(79.6)	1,624	(77.9)	1.4	.2335
Looked for info about the side-effects of medicines or vaccines (missing=1)	2,570	(78.9)	966	(82.4)	1,604	(76.9)	13.6	.0002
Please indicate if you have each of the following…								
Tablet computer (e.g., Apple iPad, Samsung Galaxy, Motorola Xoom, or Kindle Fire)	1,696	(52.1)	511	(43.6)	1,185	(56.8)	52.4	<.0001
Smartphone (e.g., Apple iPhone, Android phone, Blackberry, or Windows phone)	3,206	(98.4)	1,155	(98.6)	2,051	(98.3)	0.2	.6192
Basic cell phone only	50	(1.5)	19	(1.6)	31	(1.5)	-	.7679*
Do not have any of the above	10	(0.3)	4	(0.3)	6	(0.3)	-	.2426
Have apps related to health or wellness on tablet/smartphone (missing=26)								
Yes 1	2,640	(81.7)	935	(80.5)	1,705	(82.4)	1.8	.4049
No 2	568	(17.6)	218	(18.8)	350	(16.9)		
Don’t Know 3	24	(0.7)	9	(0.8)	15	(0.7)		
Has tablet or smartphone…								
Helped track progress on health-related goal like quitting smoking, losing weight, or increasing physical activity? (missing=27)	2,093	(64.8)	718	(61.8)	1,375	(66.4)	6.8	.0089

N = 3,258		Total		TGNB ALL		CISGENDER ALL			
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	**X^2**	***p*-value**
Helped you make a decision about how to treat an illness or condition? (missing=28)	1,340	(41.5)	468	(40.3)	872	(42.2)	1.0	.3096
Helped you in discussions with your health care provider? (missing=30)	1,906	(59.1)	709	(61.2)	1,197	(57.9)	3.4	.0658
Used an electronic wearable device to monitor/track your health or activity (e.g. FitBit, Apple iWatch, or Garmin Vivofit) (missing=1)	1,293	(39.7)	382	(32.6)	911	(43.7)	38.3	<.0001
How often did you use wearable device to track your health in past month?								
Every day 1	718	(55.5)	200	(52.4)	518	(56.9)	10.7	.0307
Almost every day 2	280	(21.7)	77	(20.2)	203	(22.3)		
1-2 times per week 3	76	(5.9)	30	(7.9)	46	(5.1)		
Less than once per week 4	72	(5.6)	19	(5.0)	53	(5.8)		
Did not use device past month 5	147	(11.4)	56	(14.7)	91	(10.0)		
Would you be willing to share health data from your wearable device with…								
Healthcare provider (missing=1,965)	1,111	(85.9)	321	(84.0)	789	(86.7)	1.5	.2252
Family and friends (missing=1,965)	770	(59.6)	215	(56.2)	555	(60.9)	2.4	.1210
Used an electronic monitoring device to monitor or track your health (e.g., glucometer, or digital BP device) (missing=2)	2,654	(81.5)	209	(17.9)	393	(18.9)	0.5	.4802
Shared health info from either electronic monitoring device or smartphone with a health professional	692	(21.2)	253	(21.6)	439	(21.1)	0.1	.7268

N = 3,258			TGNB		CISGENDER			
		Total	ALL		ALL			
Characteristic	**n**	**(%)**	**n**	**(%)**	***n***	**(%)**	**X^2**	***p*-value**
in past 12-months (missing=2)								
Used Internet for any of the following reasons in past 12-months…								
To visit a social networking site, such as Facebook or Linked In	3,141	(96.4)	1,128	(96.3)	2,013	(96.5)	.1407	.7076
To share health info on social networking sites such as Facebook, Twitter, or Instagram (missing=1)	1,082	(33.2)	448	(38.2)	634	(30.4)	20.9	<.0001
To write in an online diary or blog (i.e. Web log) (missing=1)	561	(17.2)	288	(24.6)	273	(13.1)	69.3	<.0001
To participate in an online forum or support group for people with a similar health or medical issue (missing=2)	983	(30.2)	537	(45.8)	446	(21.4)	212.2	<.0001
To watch a health-related video on YouTube or other online video streaming service (missing=1)	1,722	(52.9)	704	(60.1)	1,018	(48.8)	38.6	<.0001
Sent or received a text message from a doctor or other health care professional in the past 12-months								
Yes 1	1,801	(55.3)	679	(57.9)	1,122	(53.8)	11.6	.0030
No 2	1,381	(42.4)	457	(39.0)	924	(44.3)		
Don’t know 3	76	(2.3)	36	(3.1)	40	(1.9)		
How useful do you feel the Internet is in helping you make decisions about your health? (missing=1)								
Very useful 5	733	(22.5)	287	(24.5)	446	(21.4)	48	.3066
Useful 4	2,033	(62.4)	707	(60.4)	1,326	(63.6)		
Unsure 3	394	(12.1)	140	(12.0)	254	(12.2)		

N = 3,258				TGNB ALL		CISGENDER ALL		
Characteristic	**Total n**	**(%)**	**n**	**(%)**	***n***	**(%)**	X^2	***p*-value**
Not useful	88	(2.7)	34	(2.9)	54	(2.6)		
Not Useful at all	9	(0.3)	3	(0.3)	6	(0.3)		
How important is it for you to be able to access health resources on the Internet? (missing=1)								
Very important 5								
Important 4	1,771	(54.4)	673	(57.5)	1,098	(52.7)	8.0	.0928
Unsure 3	1,264	(38.9)	430	(36.7)	831	(40.0)		
Not important 2	153	(4.7)	46	(3.9)	107	(5.1)		
No important at all 1	62	(1.9)	20	(1.7)	42	(2.0)		
	6	(0.2)	2	(0.2)	4	(0.2)		

*Fishers exact test for cell size <30

Table 5. 4 HPV Vaccine & Number of Doses

(*N* = 3,258)			TGNB ALL		CISGENDER ALL			
	Total							
Item	***n***	**(%)**	***n***	**(%)**	***n***	**(%)**	X^2	***p*-value**
Ever received HPV vaccine?								
Yes	1,528	(46.9)	654	(55.8)	874	(41.9)	70.3	<.0001
No	1,446	(44.4)	412	(35.2)	1,034	(49.6)		
Doctor refused when asked	109	(3.4)	33	(2.8)	76	(3.7)		
I don't know	174	(5.3)	73	(6.2)	101	(4.8)		
Reported doses ever received HPV vaccine (missing=1)								
HPV Vaccine [1-dose]	121	(7.9)	56	(8.6)	65	(7.5)	18.8	.0009
HPV Vaccine [2-doses]	197	(12.9)	87	(13.3)	110	(12.6)		
HPV Vaccine [3-doses]	1,004	(65.8)	401	(61.3)	603	(69.1)		
Don't know / cannot recall	201	(13.2)	110	(16.9)	91	(10.4)		

Table 5. 5 HPV Knowledge

(*n* = 3,053)			TGNB ALL		CISGENDER ALL			
	Total							
Item	***n***	**(%)**	***n***	**(%)**	***n***	**(%)**	X^2	***p*-value**
Ever heard of HPV? (missing=1)								
Yes	3,053	(93.7)	1,107	(94.5)	1,946	(93.3)	3.3	.1913
No	176	(5.4)	53	(4.5)	123	(5.9)		
I don't know	28	(0.9)	12	(1.0)	16	(0.8)		

Table 5. 6 Receipt of HPV Vaccine

		Total		Group		Ref		
Group / Receipt of Vaccine	***n***	**(%)**	***n***	**(%)**	***n***	**(%)**	**PR**	**95% CI**
A1. Transgender ALL vs Cisgender ALL				**TGNB**		**Cisgender**		
Received HPV vaccine (ever)	1,528	(49.6)	654	(59.5)	874	(44.1)	**1.3**	**1.3-1.4**
Initiated/Completed (*n*=1,322)								
Initiated (1-dose)	121	(7.9)	56	(8.6)	65	(7.5)	1.2	0.8-1.6
Completed (3-doses)	1,004	(76.0)	401	(73.7)	603	(77.5)	0.9	0.8-1.0
A2. Gender Identity (Transgender)				**Transman SAAB Female**		**Transwoman SAAB Male**		
Received HPV vaccine (ever)	1,239	(38.1)	656	(65.7)	81	(33.8)	**2.0**	**1.6-2.3**
Initiated/Completed (*n*=611)								
Initiated (1-dose)	64	(10.5)	51	(9.4)	13	(19.7)	**0.5**	**0.3-0.9**
Completed (3-doses)	453	(74.1)	409	(75.1)	44	(66.7)	1.1	0.9-1.4
A3. Gender Identity (Cisgender)				**Cisgender SM Female**		**Cisgender SM Male**		
Received HPV vaccine (ever)	1,984	(61.0)	647	(57.5)	227	(26.4)	**2.2**	**1.9-2.5**
Initiated/Completed (*n*=778)								
Initiated (1-dose)	65	(8.4)	21	(10.2)	44	(7.7)	0.7	0.5-1.2
Completed (3-doses)	603	(77.5)	144	(69.9)	459	(80.2)	1.1	1.0-1.2
1.4								
B1. Gender Identity + Organs Born With				**TGNB Organs Born Female**		**Cisgender Female Organs Born Female**		
Received HPV vaccine (ever)	2,014	(61.8)	586	(66.1)	647	(57.4)	**1.2**	**1.1-1.2**
Initiated/Completed (*n*=1,060)								
Initiated (1-dose)	88	(8.3)	44	(9.0)	44	(7.7)	1.1	0.7-1.7
Completed (3-doses)	822	(77.6)	363	(74.4)	459	(80.2)	**0.9**	**0.8-0.9**

	Total		Group		Ref			
Group / Receipt of Vaccine	***n***	**(%)**	***n***	**(%)**	***n***	**(%)**	**PR**	**95% CI**
B2. Gender Identity + Organs Born With			**TGNB Organs Born Male**		**Cisgender Male Organs Born Male**			
Received HPV vaccine (ever)	1,079	(33.1)	70	(32.0)	227	(26.4)	1.2	1.0-1.5
Initiated/Completed (*n*=264)								
Initiated (1-dose)	33	(12.5)	12	(20.7)	21	(10.2)	1.9	1.0-3.6
Completed (3-doses)	183	(69.3)	39	(67.2)	144	(69.9)	0.9	0.7-1.1
C1. Organs Born With			**Organs Born Female Organs Now Male**		**Organs Born Female Organs Now Female**			
Received HPV vaccine (ever)	2,003	(61.5)	7	(36.8)	1,220	(61.5)	0.6	0.3-1.1
Initiated/Completed (*n*=1,055)								
Initiated (1-dose)	88	(8.3)	0	(0)	88	(8.4)		
Completed (3-doses)	817	(77.4)	4	(80.0)	813	(77.4)	0.9	0.5-1.6
C2. Organs Born With			**Organs Born Male Organs Now Female**		**Organs Born Male Organs Now Male**			
Received HPV vaccine (ever)	1,076	(33.0)	2	(11.8)	294	(27.8)	0.4	0.1-1.6
Initiated/Completed (*n*=263)								
Initiated (1-dose)	33	(12.6)	1	(50.0)	32	(12.3)	**4.6**	**1.1-19.1**
Completed (3-doses)	182	(69.2)	1	(50.0)	181	(69.4)	0.8	0.2-3.2
D1. Gender Identity + Organs Now + SAAB			**TGNB Organs Now Female AFAB**		**Cisgender Organs Now Female AFAB**			
Received HPV vaccine (ever)	1,964	(60.3)	562	(66.9)	646	(57.5)	**1.2**	**1.1-1.3**
Initiated/Completed (*n*=1,039)								
Initiated (1-dose)	88	(8.5)	44	(9.4)	44	(7.7)	1.2	0.8-1.7
Completed (3-doses)	803	(77.3)	345	(73.7)	458	(80.2)	**0.9**	**0.8-0.9**

	Total		Group		Ref			
Group / Receipt of Vaccine	***n***	**(%)**	***n***	**(%)**	***n***	**(%)**	**PR**	**95% CI**
D2. Gender Identity + Organs Now + SAAB				**TGNB Organs Now Male AMAB**		**Cisgender Organs Now Male AMAB**		
Received HPV vaccine (ever)	898	(27.6)	10	(25.6)	227	(26.4)	1.0	0.6-1.7
Initiated/Completed (*n*=215)								
Initiated (1-dose)	24	(11.2)	3	(33.3)	21	(10.2)	**3.2**	**1.2-9.1**
Completed (3-doses)	148	(68.8)	4	(44.4)	144	(69.9)	0.6	0.3-1.4
E1. Transgender Binary Identity				**Transmasculine**		**Transfeminine**		
Received HPV vaccine (ever)	732	(22.5)	232	(60.4)	197	(56.6)	1.1	0.9-1.2
Initiated/Completed (*n*=357)								
Initiated (1-dose)	39	(10.9)	16	(8.4)	23	(13.9)	0.6	0.3-1.1
Completed (3-doses)	257	(72.0)	137	(71.7)	120	(72.3)	1.0	0.8-1.1
F1. Transgender Nonbinary Identity				**Nonbinary AFAB**		**Nonbinary AMAB**		
Received HPV vaccine (ever)	826	(25.4)	483	(67.5)	47	(42.7)	**1.6**	**1.3-2.0**
Initiated/Completed (*n*=440)								
Initiated (1-dose)	41	(9.3)	36	(8.9)	5	(13.5)	0.7	0.3-1.7
Completed (3-doses)	331	(75.2)	304	(75.4)	27	(73.0)	1.1	0.9-1.4
F2. Trans Nonbinary Identity ALL vs Trans Binary Identity ALL				**Trans Nonbinary ALL**		**Trans Binary ALL**		
Received HPV vaccine (ever)	1,558	(47.8)	530	(64.1)	429	(51.9)	**1.2**	**1.1-1.3**
Initiated/Completed (*n*=797)								
Initiated (1-dose)	80	(10.0)	41	(9.3)	39	(10.9)	0.8	0.5-1.3
Completed (3-doses)	588	(73.8)	331	(75.2)	257	(72.0)	1.1	1.0-1.2

AFAB (Assigned Female at Birth), AMAB (Assigned Male at Birth), SM (Sexual Minority)
Robust Poisson method used to calculate PR (Prevalence Ratio)

Table 5. 7 Bivariate Analysis
Outcome: Receipt of HPV Vaccine EVER

N=3,258	HPV Vaccine received		HPV Vaccine Not Received			
Item	***n***	**(%)**	***n***	**(%)**	X^2	***p*-value**
GENDER IDENTITY (missing=93)						
TGNB	654	(59.5)	445	(40.5)	67.6	**<.0001**
CISGENDER (GROUP_A1)	874	(44.1)	1,110	(56.0)		
HEALTH INFORMATION SEEKING						
Used computer, smartphone, other electronic means to look for health or medical info in past year (HINTS_B5a_N) (missing=175)	1,504	(50.1)	1,499	(49.9)	12.6	**.0004**
Used Internet to look for info about vaccines in past year (HINTS_B3_N) (missing=183)	484	(47.0)	546	(53.0)	4.2	**.0405**
KNOWLEDGE/BELIEFS						
Heard of HPV	1,466	(50.6)	1,431	(49.4)	17.0	**<.0001**
INTERNET USE (past year)						
Visited a social networking site such as Facebook or LinkedIn in (HINTS_B14a_N) (missing=175)	1,500	(50.5)	1,472	(49.5)	27.3	**<.0001**
Shared health info on social networking sites (e.g. Facebook, Twitter, or Instagram) (HINTSB14b_N) (missing=176)	520	(50.9)	502	(49.1)	1.1	.2965
Wrote in online diary or BLOG (i.e., Web log) (HINTS_B14c_N) (missing=176)	279	(53.9)	239	(46.1)	4.6	**.0326**
Participated in an online forum or support group for people with a similar health or medical issue (HINTS_B14d_N) (missing=177)	466	(50.6)	455	(49.4)	0.5	.4672
Watched a health-related video on YouTube or other online video streaming service (HINTS_B14e) (missing=176)	842	(51.9)	779	(48.1)	7.7	**.0057**
Used computer, smartphone, other electronic means to…(HINTS_B5)						
Purchase medications online (HINTS_B5b) (missing=176)	619	(45.0)	757	(55.0)	20.7	**<.0001**
Email doctor's office (HINTS_B5c) (missing=179)	1,294	(50.5)	1,269	(49.5)	4.9	**.0271**
Track healthcare charges/costs (HINTS_B5d) (missing=180)	1,147	(52.4)	1,043	(47.6)	23.2	**<.0001**

N=3,258 Item	HPV Vaccine received *n*	(%)	HPV Vaccine Not Received *n*	(%)	X^2	*p*-value
Look up test results (HINTS_B5e) (missing=177)	1,189	(48.5)	1,262	(51.5)	5.6	**.0177**
Make appointments with healthcare providers (HINTS_B5f) (missing=178)	1,269	(52.5)	1,150	(47.5)	39.2	**<.0001**
Look-up info on side-effects of medications/vaccines (HINTS_B5g) (missing=176)	1,225	(50.4)	1,208	49.7)	2.7	**.0973**
SITUATION – BARRIERS TO CARE (past year)						
Were delayed in getting medical care, tests or treatments you or health care provider believed necessary (DELAYCARE) (missing=176)	546	(56.5)	421	(43.5)	26.7	**<.0001**
Needed to see a health care provider but did not because thought would be disrespected or mistreated (ANTMEDDISC) (missing=175)	332	(61.1)	211	(38.9)	35.4	**<.0001**
Less than 50% health care providers aware of Sexual Orientation (NOS_SM6_N) (missing=175)	509	(58.1)	1,019	(46.2)	35.7	**<.0001**
Less than 50% health care providers aware of Gender Identity (NOS_GM6_N) (Exclude=1,777 not gender minority)	322	(59.0)	450	(53.4)	4.1	**.0428**
SITUATION – ACCESS TO CARE						
Have a Primary Care Provider (PCP_N) (missing=214)	1,224	(47.4)	1,361	(52.7)	26.3	**<.0001**
Saw PCP in past 12-months (PCP_LASTYEAR_N) (missing=693)	1,082	(47.4)	1,203	(52.7)	0.03	.8731
Have Health Insurance (Any Type) (INSURANCE_N) (missing=175)	1,452	49.4	1,488	50.6	0.2	.6313
Medicaid (missing=175)	22	(11.1)	177	(88.9)		**<.0001**
SITUATION – PREVENTIVE CARE						
Had HIV test in past year (HIVTEST_YEAR_N) (missing=223)	625	(53.6)	541	(46.4)	12.6	**.0004**
Had anal/rectal cancer screening	233	(26.9)	1,246	(58.6)	248.5	**<.0001**
Received vaccines other than HPV ever (VAX_EVER_N)	1,503	(50.5)	1,472	(49.5)	33.2	**<.0001**

N=3,258	HPV Vaccine received		HPV Vaccine Not Received			
Item	***n***	**(%)**	***n***	**(%)**	X^2	***p*-value**
Number of vaccines received since 18-years old (missing=483) (VAX_NUM_N)						
0 vaccines (ref)	40	(57.1)	30	(42.9)	4.1	**.1293**
1-2 vaccines	145	(54.7)	120	(45.3)		
3 or more vaccines	1,206	(49.4)	1.234	(50.6)		
DEMOGRAPHICS						
Age ≤ 27 (AGE_YOUNG) (missing=175)	889	(83.8)	171	(16.1)	760.5	**<.0001**
Race (RACE_N) (missing=175)						
American Indian/Alaska Native	2	(20.0)	8	(.80)	13.2	**.0678**
Asian	45	(63.4)	26	(36.6)		
Black, African American, or African	36	(58.1)	26	(41.9)		
Hispanic, Latino or Spanish	40	(51.3)	38	(48.7)		
Middle Eastern, or North African	7	(70.0)	3	(30.0)		
Native Hawaiian or other Pacific Islander	2	(66.7)	1	(33.3)		
White (ref)	1,376	(49.0)	1,432	(51.0)		
Other	20	(50.0)	20	(50.0)		
Education Attainment (ED_LEVEL_N) (missing=175)						
High school or less	72	(59.0)	50	41.0)	4.5	**.0331**
Greater than High school	1,456	(49.2)	1,505	(50.8)		

*Fishers statistic for cell size <30, Entry criteria for preliminary main effects model $p < .25$

Table 5. 8 Multivariable Logistic Regression
HPV Vaccine EVER

(*N* = 3,258) Independent Variables	**Bivariate Analysis** *p*-value	**Preliminary Model** *p*-value	**Reduced Model** aOR (95% CI)
GENDER IDENTITY			
TGNB ALL ref: CISGENDER ALL	<.0001	.0607[+]	**aOR=1.5 (1.1-2.2)**
ONLINE HEALTH INFORMATION SEEKING			
Looked for health info past year	.0004	.1958	
Look for vaccine info past year	.0405	.0193	**aOR=0.7 (0.5-0.9)**
KNOWLEDGE/BELIEFS			
Heard of HPV	<.0001	.0091	**aOR=2.1 (1.1-4.1)**
INTERNET USE			
Visited social networking site e.g. Facebook	<.0001	.0456	**aOR=2.4 (1.1-5.6)**
Shared health info online	.2965		
Wrote in Blog	.0326	.9159	
Participated in online support group	.4672		
Watched health video online e.g. YouTube	.0057	.2306	
Purchased meds online	<.0001	.7303	
Emailed doctor's office	.0271	.2555	
Tracked healthcare charges/costs	.0001	.0058	**aOR=0.6 (0.5-0.9)**
Looked up test results	.0177	.5708	
Made appointments with health care providers online	<.0001	.0046	**aOR=0.5 (0.4-0.9)**
Looked up info on side-effects of meds/vaccines		.9751	
SITUATION – BARRIERS TO CARE			
Delayed medical care/tests/treatments in past year	<.0001	.0355	**aOR=1.5 (1.1-2.0)**
Anticipated disrespect/mistreatment, avoided provider	<.0001	.2207	
Less than 50% providers aware of Sexual Orientation	<.0001	.0304[+]	aOR=0.7 (0.5-1.0)
Less than 50% of providers aware of Gender Identity	.0428	.0555[+]	aOR=1.5 (1.0-2.1)
SITUATION – ACCESS TO CARE			
Have a Primary Care Provider (PCP)	<.0001	.1289	
Saw PCP last year	.8731		
Health Insurance (any)	.6313		
Medicaid	<.0001	.0035	**aOR=0.3 (0.1-0.7)**
SITUATION – PREVENTIVE CARE			
HIV test past year	.0004	<.0001	**aOR=2.0 (1.5-2.8)**
Received vaccines other than HPV (ever)	<.0001	--	
Number of vaccines received since 18-years old	.1293		
0 (ref)		ref	
1-2		.1491	aOR=1.8 (0.7-4.4)
3+		.0015	**aOR=3.5 (1.5-8.2)**
Had anorectal cancer screening	<.0001	.0006	**aOR=0.6 (0.4-0.8)**
DEMOGRAPHICS			
Age ≤ 27	<.0001	<.0001	**aOR=0.08 (0.05-0.11)**
Race/Ethnicity ref: White	.0678	.0098	aOR=1.0 (0.9-1.1)
Education High school or less	.0331	.7283	aOR=1.0 (0.5-2.0)
χ^2		274.1 *df*=32, *p* < .0001	276.6, *df*=17, *p* < .0001
Nagelkerke R^2		34.3%	32.8%
Hosmer and Lemeshow test		*p* = .7162	*p* = .2835
AIC score		1,528.2	1,546.8

[+]Independent variable of interest retained, --Removed due to collinearity,

Table 5. 9 Multivariable Logistic Regression
HPV Vaccine Initiated (1-dose)

(*n* = 1,528) (missing=138) **Independent Variables**	**Bivariate Analysis** *p*-value	**Preliminary Model** *p*-value	**Reduced Model** aOR (95% CI)
GENDER IDENTITY			
TGNB ALL ref: CISGENDER ALL	.4201	.9923[+]	aOR=1.3 (0.9-2.0)
ONLINE HEALTH INFORMATION SEEKING			
Looked for health info past year	.4022	.0152	
Look for vaccine info past year	<.0001	<.0001	**aOR=2.7 (1.8-4.1)**
KNOWLEDGE/BELIEFS			
Heard of HPV	.4950		
INTERNET USE			
Visited social networking site e.g. Facebook	.0493	.1783	
Shared health info online	.0083	.2982	
Wrote in Blog	.7886		
Participated in online support group	.5504		
Watched health video online e.g. YouTube	.1631	.0895	
Purchased meds online	.2430	.6677	
Emailed doctor's office	.0024	.9532	
Tracked healthcare charges/costs	.5267		
Looked up test results	.0206	.0951	
Made appointments with health care providers online	.9707		
Looked up info on side-effects of meds/vaccines	.4751		
SITUATION – BARRIERS TO CARE			
Delayed medical care/tests/treatments in past year	.8068		
Anticipated disrespect/mistreatment, avoided provider	.0257	.3255	
Less than 50% providers aware of Sexual Orientation	.0016	.0359	*
Less than 50% of providers aware of Gender Identity	.1465	.7946	
SITUATION – ACCESS TO CARE			
Have a Primary Care Provider (PCP)	.1634	.0296	*
Saw PCP last year	.5250		
Health Insurance (any)	.0271	.8312	
Medicaid	.8375		
SITUATION – PREVENTIVE CARE			
HIV test past year	.3240		
Received vaccines other than HPV (ever)	.0005	--removed	
Number of vaccines received since 18-years old	.0112	.0065	
0 (ref)			ref
1-2			aOR=0.9 (0.3-2.6)
3+			**aOR=0.3 (0.1-0.9)**
Had anorectal cancer screening	.7807		
DEMOGRAPHICS			
Age ≤ 27	.0548	.0064	**aOR=1.8 (1.2-2.8)**
Race/Ethnicity ref: White	.9821	.1945	
Education High school or less	.7538	.5640	
χ^2		50.6, *df*=17, *p* <.0001	37.4, *df*=5, *p* < .0001
Nagelkerke R^2		8.6%	2.7%
Hosmer and Lemeshow test		*p* = .3853	*p* = .7774
AIC score		351.2	718.2

[+]Independent variable of interest retained, --Removed due to collinearity, *Removed from reduced model alpha .05

Table 5. 10 Multivariable Logistic Regression
HPV Vaccine Completed (3-doses)

(*n* = 1,528) missing=416 **Independent Variables**	**Bivariate Analysis** *p*-value	**Preliminary Model** *p*-value	**Reduced Model** aOR (95% CI)
GENDER IDENTITY			
TGNB ALL ref: CISGENDER ALL	.0018	.7156[+]	**aOR=0.7 (0.5-0.9)**
ONLINE HEALTH INFORMATION SEEKING			
Looked for health info past year	.0124	.1706[+]	**aOR=3.8 (1.4-10.5)**
Look for vaccine info past year	.2963	.3336[+]	aOR=0.7 (0.6-1.0)
KNOWLEDGE/BELIEFS			
Heard of HPV	.9630		
INTERNET USE			
Visited social networking site e.g. Facebook	.0101	.1463	
Shared health info online	.1086	.8811	
Wrote in Blog	.0007	.0734	
Participated in online support group	.7973		
Watched health video online e.g. YouTube	.6451		
Purchased meds online	.0008	.4955	
Emailed doctor's office	<.0001	.4795	
Tracked healthcare charges/costs	<.0001	.8529	
Looked up test results	<.0001	.0625	
Made appointments with health care providers online	.0012	.7622	
Looked up info on side-effects of meds/vaccines	.0209	.2145	
SITUATION – BARRIERS TO CARE			
Delayed medical care/tests/treatments in past year	.5925		
Anticipated disrespect/mistreatment, avoided provider	.0645	.9743	
Less than 50% providers aware of Sexual Orientation	<.0001	.1294	
Less than 50% of providers aware of Gender Identity	.0568	.5430	
SITUATION – ACCESS TO CARE			
Have a Primary Care Provider (PCP)	.0544	--	
Saw PCP last year	.0114	.0133	**aOR=0.5 (0.3-0.8)**
Health Insurance (any)	.0327	.3205	
Medicaid	.5102		
SITUATION – PREVENTIVE CARE			
HIV test past year	.4189		
Received vaccines other than HPV (ever)	.0035	--	
Number of vaccines received since 18-years old		.0049	
0 (ref)			
1-2		.0533	**aOR= 4.8 (1.9-12.2)**
3+		.0061	**aOR= 6.7 (2.8-16.1)**
Had anorectal cancer screening	.1228	.4114	
DEMOGRAPHICS			
Age ≤ 27	.1225	.2204	aOR=0.9 (0.7-1.1)
Race/Ethnicity ref: White	.1115	.5229	aOR=1.1 (1.0-1.2)
Education High school or less	<.0001	.0217	aOR=1.8 (1.0-3.4)
χ^2		561.7, *df*=5, *p* < .0001	48.8, *df*=9, *p* < .0001
Nagelkerke R^2		11.3%	4.8%
Hosmer and Lemeshow test		*p* = .4067	*p* = .6760
AIC score		1,300.5	1,378.9

[+]Independent variable of interest retained, --Removed due to collinearity

Chapter 6: Conclusions

The goal of this dissertation is to compare human papilloma virus (HPV) vaccination rates among transgender and gender nonbinary (TGNB) people and cisgender sexual minority people; and explore how online health information seeking, electronic health (eHealth) literacy, general health literacy and other factors may be associated with receipt of HPV vaccine among these communities. The dissertation is comprised of three studies; the first, an integrative review of the literature that explores barriers to and facilitators for HPV vaccination among TGNB people; the second, a cross-sectional secondary analysis of responses to the PRIDE Study 2018-19 Annual Questionnaire; and the third, a cross-sectional analysis of responses from a novel online survey that recruited active participants from the PRIDE Study cohort. This chapter summarizes the studies included in the dissertation, reviews key findings, and discusses implications of the findings for clinical practice, health policy and future avenues of research.

Summary of Results and Key Findings

The first dissertation study involved an integrative review of the literature to explore barriers to and facilitators for HPV vaccination among TGNB people. The review found that TGNB people are under-represented in HPV vaccination research and the studies retained in the review included both sexual minority people and gender minority people and rarely distinguished TGNB people in the reporting of results. The review identified key barriers to vaccination at the individual-level; lack of HPV knowledge and misconceptions that vaccine is only for individuals who were assigned female sex assigned at birth, or that the vaccine may not necessary depending on gender affirmation surgery status. Provider recommendation is a key facilitator for vaccination but lack of cultural competence in caring for gender minority people is a barrier to

vaccination. At the systems-level cost of vaccine and lack of insurance are barriers to vaccination, and limited national recommendations for gender minority people, and omission of gender minority people in national vaccine surveillance are potential barriers to vaccination.

The second study consisted of cross-sectional secondary analysis of participant responses from The PRIDE Study Annual Questionnaire 2018-19, a large-scale long-term U.S.-based national health study of adult SGM people. A total of (N = 5,500) responses were analyzed to compare rates of HPV vaccination among TGNB participants and cisgender sexual minority participants. The Integrative Model of eHealth Use (IMeHU) guided this study and focused on factors that may be associated with HPV vaccination like HPV knowledge, situation factors (*e.g.*, barriers to care, access to care, preventive care), Internet use, and demographics. TGNB participants in The PRIDE Study cohort reported increased prevalence of ever receiving HPV vaccine compared to cisgender sexual minority people but no differences in vaccine initiation (*e.g.*, 1-dose) and vaccine completion (*e.g.*, 3-doses). Transgender men who were assigned female at birth were more likely to receive the vaccine than transgender women who were assigned male sex at birth and this was also reflected among cisgender sexual minority females who were more likely to receive the vaccine than cisgender sexual minority males. These findings suggest that independent of gender identity, HPV vaccine disparities based on assigned sex at birth continue to exist among SGM communities. Additionally, TGNB participants who were born with female organs were more likely to receive the vaccine than cisgender sexual minority females, suggesting that TGNB people who are born with female organs may engage differently in preventative services like HPV vaccination than sexual minority women.

The third study was a cross-sectional analysis of a novel online survey of participants recruited from The PRIDE Study cohort. The objective of this study was to explore the

association of online health information seeking and the possible moderating effect of health literacy on receipt of HPV vaccine among TGNB people compared to cisgender sexual minority people. We used the IMeHU to guide this study and developed the novel survey using items drawn from validated instruments (*e.g.*, Health Information National Trends Survey 5 Cycle 3, Electronic Health Literacy Scale) and The PRIDE Study Annual Questionnaire. We sent an invitation to participate in the online survey to 17,547 current PRIDE Study participants and had a response rate of 19.2%. Of the total sample (N=3,258), 46.9% (n=1,528) reported having ever received the HPV vaccine (any doses) with a greater proportion (55.8%) of TGNB participants reporting receipt compared to cisgender participants (41.9%) ($p < .0001$). Of the participants who reported ever receiving HPV vaccine, a greater proportion (8.6%) of TGNB people reported vaccine initiation compared to (7.5%) cisgender participants ($p = .0009$). However, a lower proportion (61.3%) of TGNB participants reported vaccine completion compared to cisgender participants (69.1%) ($p = .0009$). TGNB participants had higher prevalence of receipt of HPV vaccine ever compared with cisgender participants. TGNB participants who were born with female organs, assigned female sex at birth, or female sex organs now had higher prevalence of ever receiving vaccine and vaccine completion but not vaccine initiation compared to cisgender participants. In multivariable logistic regression, we found that online health information seeking, especially when participants searched online for information about vaccines in the past year, was associated with an decrease in ever receiving HPV vaccine and but an increase in vaccine initiation among TGNB participants whereas seeking general health information was only associated with an increased vaccine completion among TGNB participants compared to cisgender participants. Factors most associated with HPV receipt were having received three-or-more vaccines other than HPV since 18-years age, receipt of HIV testing in the past year, having

heard of HPV, and having visited social networking sites like Facebook. We found no moderating effects from eHealth literacy or general literacy on the relationship between online health information seeking and receipt of vaccine ever, vaccine initiation/completion. Our findings suggest disparities in HPV vaccine receipt among SGM that mirror the general population with a bias towards people born with female sex organs. The findings also suggest that online health information seeking and social media use may be associated with health behaviors like HPV vaccination, and engagement in other preventative health behaviors like receiving multiple vaccines and getting tested for HIV may also be facilitators for HPV vaccination.

Major Contributions

These dissertation studies offer considerable contributions to what is known about HPV vaccination among TGNB people. The IMeHU is a theoretical model that has never been adapted to examine a specific health behavior outcome (*e.g.*, HPV vaccination) among TGNB communities. Moreover, the inclusion of eHealth literacy and general health literacy as moderators is an innovative adaptation of the theoretical model has also never been operationalized to explore health promoting behavior among TGNB communities.

The construction of meaningful TGNB and cisgender sexual minority comparison groups is a methodological contribution to SGM research. Standardized health terminology in gender and sexual orientation is an evolving field in health informatics (Kronk & Dexheimer, 2020). The cross-sectional studies in this dissertation provide specific heuristics including the underlying Boolean logic to distinguish TGNB sub-groups (*e.g.*, transmen vs. transwomen, transgender nonbinary vs transgender binary individuals) and cisgender sexual minority sub-groups (*e.g.*, sexual minority females vs. sexual minority males). These heuristics offer

exemplars for other researchers that may work with datasets that collect extensive sexual orientation and gender identity information; or who wish to design new instruments with inter- and intra-group comparisons in mind. Intra-group comparisons, especially among TGNB communities are lacking in the literature.

Finally, these dissertation studies fill gaps in knowledge about HPV vaccination, online health information seeking, and health literacy among TGNB people. Prior research has described lower rates of HPV vaccination in cisgender sexual minority people compared to the general population but few studies that included any TGNB people (Bednarczyk et al., 2017; Reiter et al., 2015). The HINTS instrument includes demographic questions about sexual orientation but completely omits any questions about gender identity (National Cancer Institute, 2018). Moreover, eHealth literacy has been assessed in sexual minority groups but never in TGNB communities (Horvath & Bauermeister, 2017). These dissertation studies address these gaps in knowledge about TGNB. They leverage a large-scale, national cohort study to describe HPV vaccination in a large sample of TGNB people. The studies adopt items from HINTS 5 Cycle 3 to assess health information seeking in TGNB people for the first time. Likewise, the studies leverage a validated instrument eHEALS to assess eHealth literacy in TGNB people. The results of these studies offer new knowledge about factors associated with HPV vaccination in TGNB people and how these may be different from cisgender sexual minority people.

Implications for Clinical Practice

Educating health care providers and nurses about the need for HPV vaccination in TGNB people is a first step to promoting vaccination in these communities. Because a lack of knowledge about HPV and misperceptions about the need for HPV vaccination may exist in TGNB communities, it is critical that health care providers to be well-informed of the need for

HPV vaccination for all genders and gender expressions. Studies have shown that health care providers may be misinformed about the need for vaccination in both women and men (Blackwell, 2016). Our finding that TGNB people are more likely to only initiate HPV vaccine but less like to complete HPV vaccine compared to cisgender sexual minority people highlights the need for healthcare providers to educate TGNB patients regarding vaccine dosing schedules, and provider reminders to ensure vaccine completion. To address the issue of incomplete vaccination, the efficacy of a single-dose HPV regimen has been studied and preliminary findings in a study of cisgender women showed no differences in predicted probability of HPV infection in individuals who received one, two, three doses of HPV vaccine (Sonawane et al., 2019). Yet, the current national recommendation remains for adults to complete three 'catch-up' doses if they have not received any doses by age 15-year (Meites, 2019). Additionally, studies have shown that HPV vaccination decreases HPV infection even when vaccination is not initiated in adolescence (Kang et al., 2018).

To reduce barriers care and delay in receiving care due to perceived stigma and discrimination in TGNB people, health care providers should be trained in culturally competent care of TGNB people. Unfortunately, studies have shown that undergraduate medical training spends little time on SGM health topics (Obedin-Maliver et al., 2011). There is limited literature that examines nurse and nurse practitioner training in culturally competent SGM care despite studies that have shown that negative attitudes exist when nurses care for LGBT patients (Dorsen, 2012; Dorsen & Van Devanter, 2016). Culturally competent care of TGNB should at a minimum train clinicians about how to sensitively discuss gender identity with their patients (Maragh-Bass et al., 2017). Providing a health care environment that affirms gender diversity has

been associated with increased rates of vaccination in TGNB communities (Apaydin, Fontenot, Shtasel, et al., 2018).

Our finding that greater proportions of TGNB than cisgender sexual minority participants reported delaying health care or putting off care because of concern that they would be disrespected or mistreated further highlights the need for culturally competent TGNB care. Studies have shown that a lack of SGM competence among providers is a barrier to vaccination in SGM communities (Blackwell, 2016; Wheldon, Sutton, et al., 2018). For example, studies of rural-residing sexual minority women found that health care providers routine did not ask about sexual orientation and patients avoided or delayed preventive care due to fear of discrimination based on their sexual orientation (Barefoot et al., 2017).

We did not find an association between the proportion of health care providers aware of a participant's sexual orientation or gender identity and the HPV vaccination outcomes. Yet, research has shown that that SGM people who are less 'out' to their medical providers and others in general are also less likely to engage in primary care services including preventive vaccination (Whitehead et al., 2016). Health care providers should be reminded that asking about a patient's sexual orientation and gender identity is an important practice in the care of both TGNB and sexual minority people. Lastly, our findings that receipt of other vaccines and/or HIV testing increases receipt of HPV vaccine in TGNB people is consistent with the literature that has shown that 'bundled' preventative services may promote vaccine uptake in sexual minority communities, and this should be explored further for TGNB people (Apaydin, Fontenot, Borba, et al., 2018; Fontenot et al., 2016).

Implications for Health Policy

Transgender people were explicitly added to the recommendation for HPV vaccination in December 2016, but there has been little done to describe vaccine uptake in TGNB people since the policy was updated (Meites, 2016). Although there have been calls for the collection of gender identity information in the electronic health record and survey instruments by the Office of the National Coordinator and the NIH SGM Research Office, TGNB people are still missing from national surveys (Cahill & Makadon, 2014; National Institutes of Health, 2019). The Behavioral Risk Factor Surveillance System (BRFSS) has collected sexual orientation and gender identity information (SOGI) and includes items that assess receipt of HPV vaccine, however both the SOGI module and adult HPV vaccination module are considered optional, and to-date 30 states have implemented the SOGI module and only nine states have implemented the adult HPV vaccination module (Baker, 2018; Centers for Disease Control and Prevention, 2018).

Given the dearth of research that describes HPV vaccination in TGNB people, this dissertation research highlights the need for data collection at the national level to inform health policy. It is unknown whether disparities exist in HPV vaccination rates in adult TGNB using national probability sampling because these data are not yet being collected for TGNB communities. Furthermore, given the recent ACIP update that expanded the recommended age range from 9 through 26 years to 9 through 45 years for both women and men, the collection of adult HPV vaccination information is now critical for vaccine surveillance across all communities.

Finally, our finding of a bias for receipt of HPV vaccine for people who were assigned female sex assigned at birth and confusion among TGNB people regarding the need for HPV vaccine highlights the need for an update to the ACIP recommendation to do more than just

recommend HPV vaccination for transgender people and instead, include HPV information that is targeted for TGNB communities that specifically addresses misconceptions that may exist regarding assigned sex at birth and gender affirmation surgery.

During the writing of this dissertation, the SARS-CoV-2 (COVID-19) pandemic is unfolding globally. The rapidly evolving spread of COVID-19 has spurred the rapid development of vaccines to prevent further spread of the disease. It is unclear how the roll-out of new vaccines for COVID-19 will affect existing vaccines like HPV vaccine once they are made available. However, CDC surveillance suggests that the COVID-19 pandemic has already decreased pediatric vaccination, including adolescent dosing of HPV vaccine (Santoli et al., 2020). This may have population implications, thereby increasing the number of adults who have not received any doses of HPV vaccine and further compounding the lag in gender-based vaccination that originated when HPV vaccine was introduced in 2006 and was only recommended for girls (Daley et al., 2017). Moreover, there exists the phenomenon of *vaccine hesitancy* whereby fear of vaccine-preventable diseases is shifted from the infectious pathogens to the vaccines that would prevent infection (Siddiqui et al., 2013). It is unclear how new vaccines for COVID-19 may affect vaccine hesitancy for existing vaccines like HPV, and how TGNB and other SGM communities may perceive COVID-19 vaccine in relationship HPV vaccine. The data that would inform health policies for vaccine-preventable diseases is dynamically evolving. What is certain is that COVID-19 will have long-term implications for vaccine uptake, including HPV vaccination among adolescents and adults.

Implications for Future Research

Several implications for future research arise from these dissertation studies. An association may exist between health information seeking and the health-promoting behavior;

HPV vaccine receipt. However, neither eHealth literacy nor general health literacy were found to moderate this relationship. The adapted Integrative Model of eHealth Use (IMeHU) theoretical framework that informed this dissertation deserves further investigation, especially the constructs relating to health information seeking and Internet use (Bodie & Dutta, 2008). The finding in Study Number Three that use of social networking sites like Facebook increased the receipt of HPV vaccine in TGNB participants also warrants further study. It remains unclear how TGNB communities are using social media and how this may influence personal health decision-making and health behavior. It is possible that TGNB people who seek health information online may be exposed to health information through social media. Incident exposure to health information has been found to be associated with seeking health information for oneself and for someone else among cisgender sexual minority people (Jabson et al., 2017). Social media platforms like Instagram and Facebook may increase incident exposure to health information as users scroll-through content feeds which might then prompt more directed health information seeking. Although these dissertation studies found a general association between social media use and HPV vaccine receipt, there was no association observed with sharing health information on social media and the vaccine outcome. A future direction of research would be to explore health information seeking further in TGNB people using qualitative methods such as in-depth interviews or focus groups to better understand how TGNB people use social media, seek health information online and what types of information are used for personal health decision-making, like whether or not to receive a vaccine.

The results of these dissertation studies could inform interventions to improve HPV vaccine receipt among TGNB communities. At the individual patient-level, social media interventions that combine information seeking and culturally appropriate content for TGNB

people can deliver health information to encourage HPV vaccine uptake. A social media intervention that uses recognizable queer or TGNB people or even social media influencers from the community to deliver health promotion messages through video or chat may foster trust and reassurance among TGNB communities.

Interventions in the clinical setting may also be important. For example, interventions that bundle HPV vaccine with other vaccines and/or HIV testing for TGNB people is another potential avenue for research. Because clinicians may have misconceptions about HPV vaccination and the appropriateness for TGNB people, interventions that target knowledge deficits in primary care providers who order HPV vaccine are a priority area of focus. Professional clinical organizations like the American Academy of Nurse Practitioners could be leveraged to send their members targeted electronic infographic campaigns that highlight the need for HPV vaccination among all TGNB and sexual minority people. Such campaigns could be combined with links to brief clinical briefs on working TGNB patients and updates on the latest 2019 ACIP HPV vaccine recommendations. Regardless of the intervention, future HPV vaccine research must consider recruiting TGNB people as the primary community of interest. This would provide a better understanding of the unique perspective of TGNB people and distinguish them from cisgender sexual minority people. Although these studies did not observe profound differences between HPV vaccination among transgender nonbinary participants and transgender binary participants, TGNB sub-groups should be distinguished from one another in future studies to better characterize whether intra-group disparities exist.

Strengths and Limitations

These dissertation studies have both strengths and limitations. To our knowledge, this is the first study of online health information seeking among TGNB people and the first evaluation

of eHealth literacy among these communities. The studies include large samples of TGNB people that are drawn from a unique national cohort of SGM people, The PRIDE Study. Moreover, the novel survey developed from the HINTS 5 Cycle 3 survey items, PRIDE Study Annual Questionnaire, and the eHEALS instrument, enabled the exploration of novel scientific questions among a TGNB sample.

A limitation of the literature review was that it included only U.S.-based, English-language studies and may have omitted studies that describe more dedicated samples of TGNB people. The PRIDE Study cohort is a convenience sample which limits the value of probability sampling when performing secondary analysis. The sample populations in both cross-sectional analyses were predominantly White and had attained greater than high school education and this lack of demographic diversity limits the generalizability of the findings. The cross-sectional design of the quantitative studies limits any causal conclusions.

Conclusion

These dissertation studies aimed to compare the rate of HPV vaccination among TGNB communities and explore the association of factors like online health information seeking and eHealth literacy with vaccine receipt. Although higher rates of ever receiving HPV vaccine were observed in TGNB people compared to cisgender sexual minority people, there is still room to improve vaccine receipt in both TGNB and cisgender communities as the rates for each are still far below the previous Healthy People 2020 goal of 80% vaccine uptake overall. When individuals who are at increased risk of HPV infection are left unvaccinated, there may be dire consequences for those who develop HPV-associated cancer. The incidence of HPV-associated throat cancer has now exceeded that of cervical cancer and the incidence of anal cancer has doubled over that past two decades (D'Souza et al., 2017; Machalek et al., 2012; Sonawane et al.,

2017; Stier et al., 2016). Yet, TGNB people remain missing from studies of cancer prevalence. The National Cancer Institute surveillance programs neglect to collect information on gender identity, and in doing so, neglect to consider TGNB people in their population data. Studies that incorporate large representative samples of TGNB people are clearly a priority for future HPV research. Moreover, given that nearly all HPV-associated cancer can be prevented by vaccination, innovative solutions are needed to promote vaccine uptake among TGNB and cisgender sexual minority communities. The findings from these studies illuminate a potential path for future research into interventions that consider the association of online health information seeking, social media use, and the receipt of HPV vaccine.

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Appendices

Appendix A: Database Search Queries

PubMed/MEDLINE

bisexual[tiab] OR bisexuality[MeSH Terms] OR bisexuality[tiab] OR bisexuals[tiab] OR gay[tiab] OR gays[tiab] OR GLB[tiab] OR GLBT[tiab] OR homosexual[tiab] OR homosexualities[tiab] OR homosexuality[MeSH Terms] OR homosexuality[tiab] OR homosexuals[tiab] OR intersex[tiab] OR lesbian[tiab] OR lesbianism[tiab] OR lesbians[tiab] OR LGB[tiab] OR LGBT[tiab] OR "men who have sex with men"[tiab] OR msm[tiab] OR queer [tiab] OR "sexual minorities"[tiab] OR "sexual minority"[tiab] OR "sexual orientation"[tiab] OR transgender[tiab] OR transgendered[tiab] OR transgenders[tiab] OR transsexual[tiab] OR transsexualism[MeSH Terms] OR transsexualism[tiab] OR transsexuality[tiab] OR transsexuals[tiab] OR "women loving women"[tiab] OR "women who have sex with women"[tiab] OR WSW[tiab] NOT gay[au] OR "laparoscopic gastric bypass"[tiab] OR "markov state model" OR "multiple source method"[tiab]
AND
HPV[tiab] OR human papillomavirus[tiab] OR "papillomavirus vaccines"[MeSH] OR human papilloma virus* OR HPV*[tiab] OR papillomavirus*[tiab] OR immunis*[tiab] OR immuniz*[tiab] OR vaccin*[MeSH] OR vaccine*[tiab] OR vaccination*[tiab]
AND
accept*[tiab] OR attitud*[tiab] OR attitud*[tiab] OR aware*[tiab] OR barrier*[tiab] OR behavior*[tiab] OR behavior*[tiab] OR choice*[tiab] OR cognitive*[tiab] OR decision*[tiab] OR educat*[tiab] OR "eHealth literacy"[tiab] OR "electronic health literacy"[tiab] OR facilitat*[tiab] OR health information[tiab] OR "health literacy"[tiab] OR information*[tiab] OR intent*[tiab] OR knowledg*[tiab] OR knowledg*[tiab] OR literacy[tiab] OR literate[tiab] OR motivat*[tiab] OR participat*[tiab] OR percept*[tiab] OR predict*[tiab] OR primary prevention[tiab] OR refus*[tiab] OR seek*[tiab] OR social norm*[tiab] OR uncertain*[tiab] OR uptak*[tiab] OR value*[tiab]

CINAHL

bisexual OR bisexuality OR bisexuality OR bisexuals OR gay OR gays OR GLB OR GLBT OR homosexual OR homosexualities OR homosexuality OR homosexuality OR homosexuals OR intersex OR lesbian OR lesbianism OR lesbians OR LGB OR LGBT OR "men who have sex with men" OR msm OR queer OR "sexual minorities" OR "sexual minority" OR "sexual orientation" OR transgender OR transgendered OR transgenders OR transsexual OR transsexualism OR transsexualism OR transsexuality OR transsexuals OR "women loving women" OR "women who have sex with women" OR WSW NOT gay OR "laparoscopic gastric bypass" OR "markov state model" OR "multiple source method"
AND
HPV OR human papillomavirus OR "papillomavirus vaccines" OR human papilloma virus* OR HPV* OR papillomavirus* OR immunis* OR immuniz* OR vaccin* OR vaccine* OR vaccination*
AND
accept* OR attitud* OR attitud* OR aware* OR barrier* OR behavior* OR behavior* OR choice* OR cognitive* OR decision* OR educat* OR "eHealth literacy" OR "electronic health literacy" OR facilitat* OR health information OR "health literacy" OR information* OR intent* OR knowledg* OR knowledg* OR literacy OR literate OR motivat* OR participat* OR percept* OR predict* OR primary prevention OR refus* OR seek* OR social norm* OR uncertain* OR uptak* OR value*

EMBASE

bisexuality OR 'LGBT people' OR homosexuality OR intersex OR 'homosexual female' OR 'men who have sex with men' OR 'homosexual male' OR 'sexual and gender minority' OR 'sexual orientation' OR transgender OR transgenderism OR transsexualism OR transsexuality OR 'women who have sex with women' OR 'women who have sex with women and men' OR 'men who have sex with men and women'
AND
'Wart virus vaccine' OR immunization OR vaccination
AND
acceptance OR 'attitude to health' OR attitude OR awareness OR barriers OR behavior OR 'decision making' OR cognition OR education OR 'medical information' OR 'health literacy' OR behavior OR literacy OR motivation OR participation OR perception OR prediction OR 'primary prevention' OR prevention OR knowledge OR refuse OR 'social norm' OR uncertainty OR uptake OR value

Appendix B: eHealth Literacy Scale

1. How **useful** do you feel the Internet is in helping you in making decisions about your health?

❑1	❑2	❑3	❑4	❑5
Not useful at all	Not useful	Unsure	Useful	Very Useful

2. How **important** is it for you to be able to access health resources on the Internet?

❑1	❑2	❑3	❑4	❑5
Not important at all	Not important	Unsure	Important	Very important

3. I know **what** health resources are available on the Internet

1) ❑ Strongly Disagree

2) ❑ Disagree

3) ❑ Undecided

4) ❑ Agree

5) ❑ Strongly Agree

4. I know **where** to find helpful health resources on the Internet

1) ❑ Strongly Disagree

2) ❑ Disagree

3) ❑ Undecided

4) ❑ Agree

5) ❑ Strongly Agree

5. I know **how** to find helpful health resources on the Internet

1) ❑ Strongly Disagree

2) ❑ Disagree

3) ❑ Undecided

4) ❑ Agree

5) ❑ Strongly Agree

6. I know **how to use** the Internet to answer my questions about health

1) ❑ Strongly Disagree

2) ❑ Disagree

3) ❑ Undecided

4) ❑ Agree

5) ❑ Strongly Agree

7. I know how to use **the health information** I find on the Internet to help me

1) ❑ Strongly Disagree

2) ❑ Disagree

3) ❑ Undecided

4) ❑ Agree

5) ❑ Strongly Agree

8. I have the skills I need to **evaluate** the health resources I find on the Internet

1) ❑ Strongly Disagree

2) ❑ Disagree

3) ❑ Undecided

4) ❑ Agree

5) ❑ Strongly Agree

9. I can tell **high quality** health resources from **low quality** health resources on the Internet

1) ❑ Strongly Disagree

2) ❑ Disagree

3) ❑ Undecided

4) ❑ Agree

5) ❑ Strongly Agree

10. I feel **confident** in using information from the Internet to make health decisions

1) ❑ Strongly Disagree

2) ❑ Disagree

3) ❑ Undecided

4) ❑ Agree

5) ❑ Strongly Agree

Thank you!

** Note: Questions #1 and #2 are recommended as supplementary items for use with the eHEALS to understand consumer's interest in using eHealth in general. These items are not a formal part of the eHealth Literacy scale, which comprises questions #3-10.*

Appendix C: General Health Literacy Items

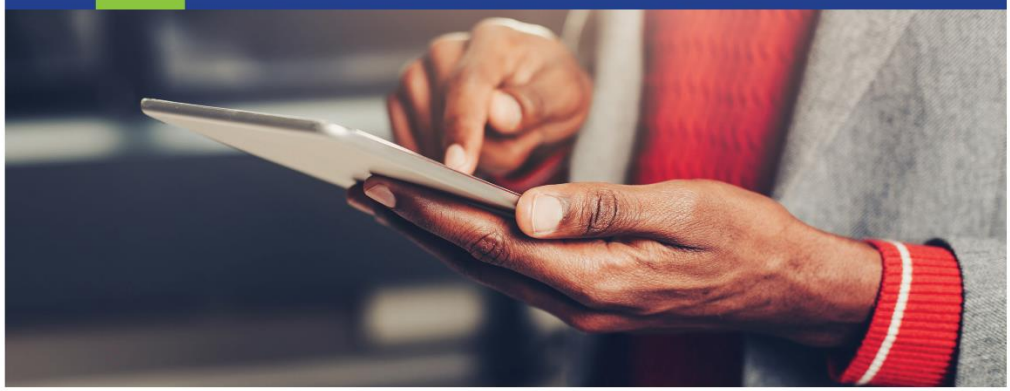
How confident are you filling out medical forms by yourself? Not at all A little bit Somewhat Quite a bit Extremely
How often have problems difficulty understanding written communication? Never Occasionally Sometimes Often Always
How often need help to read written material from doctor/pharmacy? Never Occasionally Sometimes Often Always

Note: Items not intended to be used as as a scale.

Appendix D: HINTS 5 Cycle 3

Health Information

National Trends Survey



hints

H5–C3

Annotated Form
Cycle 3/Web Pilot, English Version

START HERE:

Instructions

- Please use a black or blue pen to complete this form.
- Mark ☒ to indicate your answer.
- If you want to change your answer, mark ■ on the wrong answer.

1. Is there more than one person age 18 or older living in this household?

AdultsInHH

☐ 1 Yes

☐ 2 No → **GO TO A1 on the next page**

2. Including yourself, how many people age 18 or older live in this household?

MailHHAdults

☐☐

3. **The adult with the next birthday should complete this questionnaire.** This way, across all households, HINTS will include responses from adults of all ages.

4. Please write the first name, nickname, or initials of the adult with the next birthday. This is the person who should complete the questionnaire.

Si prefiere recibir la encuesta en español, por favor llame 1-888-738-6812

36491

A: Looking For Health Information

A1. Have you ever looked for information about health or medical topics from any source?

SeekHealthInfo

- [1] Yes
- [2] No → **GO TO A5 in the next column**

A2. The most recent time you looked for information about health or medical topics, where did you go first?

Mark only one.

WhereSeekHealthInfo
WhereSeekHealthInfo_IMP

- [1] Books
- [2] Brochures, pamphlets, etc.
- [3] Cancer organization
- [4] Family
- [5] Friend/Co-worker
- [6] Doctor or health care provider
- [7] Internet
- [8] Library
- [9] Magazines
- [10] Newspapers
- [11] Telephone information number
- [12] Complementary, alternative, or unconventional practitioner

A3. The most recent time you looked for information about health or medical topics, who was it for?

WhoLookingFor

- [1] Myself
- [2] Someone else
- [3] Both myself and someone else

A4. Based on the results of your most recent search for information about health or medical topics, how much do you agree or disagree with each of the following statements?

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree
a. It took a lot of effort to get the information you needed..... LotofEffort	1	2	3	4
b. You felt frustrated during your search for the information..... Frustrated	1	2	3	4

A5. Overall, how confident are you that you could get advice or information about health or medical topics if you needed it?

ConfidentGetHealthInf

- [1] Completely confident
- [2] Very confident
- [3] Somewhat confident
- [4] A little confident
- [5] Not confident at all

A6. In general, how much would you trust information about health or medical topics from each of the following?

	Not at all	A little	Some	A lot
a. A doctor..... TrustDoctor	4	3	2	1
b. Family or friends..... TrustFamily	4	3	2	1
c. Government health agencies... TrustGov	4	3	2	1
d. Charitable organizations..... TrustCharities	4	3	2	1
e. Religious organizations and leaders..... TrustReligiousOrgs	4	3	2	1

A7. Imagine that you had a strong need to get information about health or medical topics. Where would you go first?

StrongNeedHealthInfo

Mark only one.

StrongNeedHealthInfo_IMP

- 1 Books
- 2 Brochures, pamphlets, etc.
- 3 Cancer organization
- 4 Family
- 5 Friend/Co-worker
- 6 Doctor or health care provider
- 7 Internet
- 8 Library
- 9 Magazines
- 10 Newspapers
- 11 Telephone information number
- 12 Complementary, alternative, or unconventional practitioner
- 91 Other – Specify → StrongNeedHealthInfo_OS

A8. Have you ever looked for information about cancer from any source?

SeekCancerInfo

- 1 Yes
- 2 No

B: Using the Internet to Find Information

B1. Do you ever go on-line to access the Internet or World Wide Web, or to send and receive e-mail?

UseInternet

- 1 Yes
- 2 No → **GO TO B5 on the next page**

B2. When you use the Internet, do you access it through...

	Yes	No
a. A regular dial-up telephone line (Internet_DialUp)	1	2
b. Broadband such as DSL, cable, or FiOS (Internet_BroadBnd)	1	2
c. A cellular network (i.e., phone, 3G/4G) (Internet_Cell)	1	2
d. A wireless network (Wi-Fi) (Internet_WiFi)	1	2

B3. In the past 12 months, have you used the Internet to look for information about cancer for yourself?

InternetCancerInfoSelf

- 1 Yes
- 2 No

B4. How often do you access the Internet through each of the following?

	Daily	Sometimes	Never	Not Applicable
a. Computer at home (WhereUseInternet_Home)	1	2	3	4
b. Computer at work (WhereUseInternet_Work)	1	2	3	4
c. Computer in a public place (library, community center, other) (WhereUseInternet_PublicPlace)	1	2	3	4
d. On a mobile device (cell phone/smart phone/tablet) (WhereUseInternet_MobileDevice)	1	2	3	4

B5. In the past 12 months, have you used a computer, smartphone, or other electronic means to do any of the following?

	Yes	No
a. Looked for health or medical information for yourself..... Electronic_SelfHealthInfo	1	2
b. Bought medicine or vitamins online..... Electronic_BuyMedicine	1	2
c. Used e-mail or the Internet to communicate with a doctor or a doctor's office..... Electronic_TalkDoctor	1	2
d. Tracked health care charges and costs..... Electronic_TrackedHealthCosts	1	2
e. Looked up medical test results..... Electronic_TestResults	1	2
f. Made appointments with a health care provider..... Electronic_MadeAppts	1	2
g. Looked for information about the **harms** of electronic or e-cigarettes (also known as vapes, vape-pens, tanks, mods, or pod-mods)..... Electronic_ECigHarms	1	2

B6. Please indicate if you have each of the following.

Mark <u>all that apply</u>.

- 1 Tablet computer (for example, an iPad, Samsung Galaxy, Motorola Xoom, or Kindle Fire)
  HaveDevice_Tablet
- 1 Smartphone (for example, an iPhone, Android, Blackberry, or Windows phone)
  HaveDevice_SmartPh
- 1 Basic cell phone only
  HaveDevice_CellPh
- 1 I do not have any of the above
  HaveDevice_None

GO TO B9 in the next column

HaveDevice_Cat

B7. On your <u>tablet or smartphone</u>, do you have any "apps" related to health and wellness?

TabletHealthWellnessApps

1 Yes
2 No
3 Don't know

B8. Has your tablet or smartphone…

	Yes	No
a. Helped you track progress on a health-related goal such as quitting smoking, losing weight, or increasing physical activity?..... Tablet_AchieveGoal	1	2
b. Helped you make a decision about how to treat an illness or condition?..... Tablet_MakeDecision	1	2
c. Helped you in discussions with your health care provider?..... Tablet_DiscussionsHCP	1	2

B9. In the past 12 months, have you used an electronic wearable device to monitor or track your health or activity? For example, a Fitbit, Apple Watch, or Garmin Vivofit.

WearableDevTrackHealth

1 Yes
2 No → **GO TO B12 below**

B10. In the past month, how often did you use a wearable device to track your health?

FreqWearDevTrackHealth

1 Every day
2 Almost every day
3 1-2 times per week
4 Less than once per week
5 I did not use a wearable device in the past month

B11. Would you be willing to share health data from your wearable device with...

	Yes	No
a. your health care provider?..... WillingShareData_HCP	1	2
b. your family or friends?..... WillingShareData_Fam	1	2

B12. In the last 12 months, have you used an <u>electronic medical device</u> to monitor or track your health? For example a glucometer or digital blood pressure device.

OtherDevTrackHealth2

1 Yes
2 No

36491

B13. Have you shared health information from either an electronic monitoring device or smartphone with a health professional within the last 12 months?

SharedHealthDeviceInfo

1 Yes
2 No
3 Not Applicable

B14. Sometimes people use the Internet to connect with other people online through social networks like Facebook or Twitter. This is often called "social media".

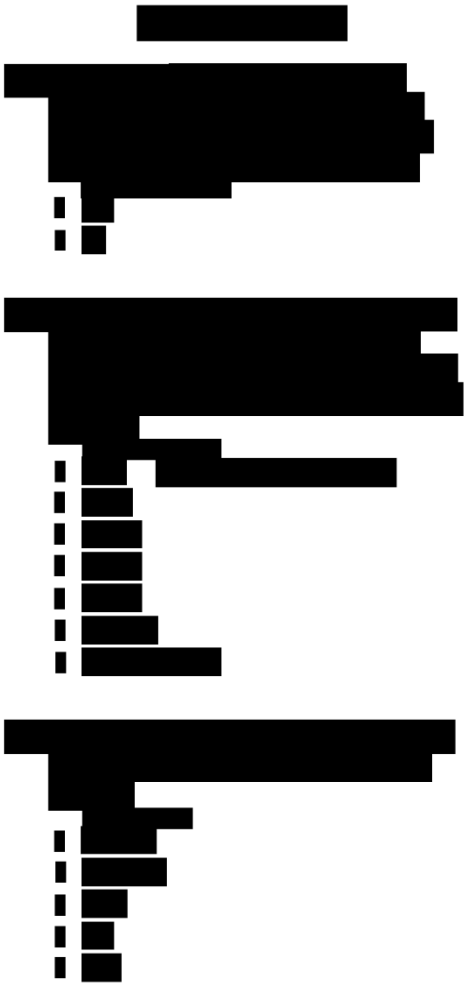
In the past 12 months, have you used the Internet for any of the following reasons?

	Yes	No
a. To visit a social networking site, such as Facebook or LinkedIn (IntRsn_VisitedSocNet)	1	2
b. To share health information on social networking sites, such as Facebook or Twitter (IntRsn_SharedSocNet)	1	2
c. To write in an online diary or blog (i.e., Web log) (IntRsn_WroteBlog)	1	2
d. To participate in an online forum or support group for people with a similar health or medical issue (IntRsn_SupportGroup)	1	2
e. To watch a health-related video on YouTube (IntRsn_YouTube)	1	2

B15. Have you sent a text message to or received a text message from a doctor or other health care professional within the last 12 months?

TextFromDoctor

1 Yes
2 No
3 Don't know



Appendix E: HPV and Health Information Seeking Survey

Start of Block: WELCOME

WELCOME_INTRO

HPV and Health Information Seeking Survey

PLEASE READ THIS

Welcome to the **HPV and Health Information Seeking Survey** of The PRIDE Study. This survey asks about human papillomavirus (also known as HPV) and how you seek health information online and offline.

WELCOME_INTRO1 Depending on the browser you are using, you may need to scroll up to the top of each survey screen to see all the questions.

Some browsers will auto-scroll to the top of each survey screen, while others do not. We recommend using **Chrome**. We apologize for the inconvenience.

Please advance to the next screen to start this survey.

End of Block: WELCOME

Start of Block: HOW TO SAVE & SURVEY INFO

SAVE_INTRO HOW TO SAVE YOUR SURVEY TO FINISH LATER

While we recommend that you complete the survey in one sitting, you can start the survey and finish it later by selecting “Save and Exit” in the upper-right corner of the screen. You will return to your Dashboard.

TPS_SAVE

To return to the survey, click on the "Continue" button for the survey you wish to continue.

STUDY_INFO

STUDY INFORMATION

We anticipate this study will take 20-30 minutes to complete. You will not be paid for taking part in this study. We will, however, hold a raffle for multiple $50 gift cards as a thank you to

interested individuals. If you complete this survey you will automatically be entered into a raffle to be conducted no later than May 1, 2020 (after the survey is closed) for a $50 gift card. The drawing will be conducted by The PRIDE Study of Stanford University in Palo Alto, California.

Participation in the study is not required in order to participate in the raffle. You can enter the raffle if you do not start or complete the study task. You can enter the drawing by contacting research@pridestudy.org.

The chance of winning a prize will vary depending on the number of people who express interest, and we estimate that it will never be worse than 1 in 1000. The winner will be notified immediately by email and provided with information on how to receive the prize. To participate in this study please click the right arrow to continue.

End of Block: HOW TO SAVE & SURVEY INFO

Start of Block: HEALTH BEHAVIOR OUTCOMES / HPV KNOWLEDGE

HPVKNOW_INTRO

The following questions are related to whether you received a vaccine (shots) to prevent human papillomavirus, also known as HPV.

Chew

Have you **EVER** heard of HPV? HPV stands for human papillomavirus. Some types of HPV increase your risk for cervical or anal cancer while others do not.

- Yes (1)
- No (0)
- I don't know (88)

HPV_SHOT Have you **EVER** received an HPV shot or vaccine? HPV stands for human papillomavirus. The vaccines are sometimes called CERVARIX® or GARDASIL®. The HPV vaccine is given as a three-dose series routinely to people from age 9-45. It was released in 2006.

- Yes (1)
- No (0)
- Health care provider refused when asked (2)
- I don't know (88)

Display This Question:

If HPV_SHOT = Yes

HPVQUANT How many HPV vaccine shots did you have?

- ○ None (0)
- ○ One (1)
- ○ Two (2)
- ○ Three or more (3)
- ○ I don't know (88)

End of Block: HEALTH BEHAVIOR OUTCOMES / HPV KNOWLEDGE

Start of Block: HISB - LOOKING FOR HEALTH INFORMATION

HISB_INTRO

The following questions are related to how you look for health information to make personal health decisions. For example, information to help you decide whether or not to get a preventative vaccine (shot).

SEEKHEALTHINFO

Have you **EVER** looked for information about health or medical topics from any source?

- ○ Yes (1)
- ○ No (2)

Display This Question:

If SEEKHEALTHINFO = Yes

HINTSA2 The most recent time you looked for information about health or medical topics, where did you go first? (Mark only one.)

- ○ Books (1)
- ○ Brochures, pamphlets, etc. (2)
- ○ Medical organization (3)
- ○ Family (4)
- ○ Friend/Co-worker (5)
- ○ Doctor or health care provider (6)
- ○ Internet (7)
- ○ Library (8)
- ○ Magazines (9)
- ○ Newspapers (10)
- ○ Telephone information number (11)
- ○ Complimentary, alternative, or unconventional practitioner (12)

Display This Question:

If SEEKHEALTHINFO = Yes

HINTSA3 The most recent time you looked for information about health or medical topics, who was it for?

- ○ Myself (1)
- ○ Someone else (2)
- ○ Both myself and someone else (3)

Page Break

Display This Question:

If SEEKHEALTHINFO = Yes

HINTS_A4 Based on the results of your most recent search for information about health or medical topics, how much do you agree or disagree with each of the following statements?

Display This Question:

If SEEKHEALTHINFO = Yes

HINTS_A4a It took a lot of effort to get the information you needed.

- Strongly agree (1)
- Somewhat agree (2)
- Somewhat disagree (3)
- Strongly disagree (4)

Display This Question:

If SEEKHEALTHINFO = Yes

HINTS_A4b You felt frustrated during your search for the information.

- ○ Strongly agree (1)
- ○ Somewhat agree (2)
- ○ Somewhat disagree (3)
- ○ Strongly disagree (4)

Page Break

HINTS_A5 Overall, how confident are you that you could get advice or information about health or medical topics if you needed it?

- ○ Completely confident (1)
- ○ Very confident (2)
- ○ Somewhat confident (3)
- ○ A little confident (4)
- ○ Not confident at all (5)

Page Break

HINTS_A6 In general, how much would you trust information about health or medical topics, such as information about vaccines, from each of the following?

HINTS_A6a A doctor or medical provider.

- ○ Not at all (4)
- ○ A little (3)
- ○ Some (2)
- ○ A lot (1)

HINTS_A6b Family or friends.

- ○ Not at all (4)
- ○ A little (3)
- ○ Some (2)
- ○ A lot (1)

HINTS_A6c Government health agencies.

- ○ Not at all (4)
- ○ A little (3)
- ○ Some (2)
- ○ A lot (1)

HINTS_A6d Charitable organizations.

- ○ Not at all (4)
- ○ A little (3)
- ○ Some (2)
- ○ A lot (1)

HINTS_A6e Religious organizations and leaders.

- ○ Not at all (4)
- ○ A little (3)
- ○ Some (2)
- ○ A lot (1)

HINTS_A6f The Internet.

- ○ Not at all (4)
- ○ A little (3)
- ○ Some (2)
- ○ A lot (1)

Page Break

HINTS_A7 Imagine you had a strong need to get information about health or medical topics, such as information on vaccines. Where would you go first? (Mark only one.)

- ○ Books (1)
- ○ Brochures, pamphlets, etc. (2)
- ○ Medical organization (3)
- ○ Family (4)
- ○ Friend/Co-worker (5)
- ○ Doctor or health care provider (6)
- ○ Internet (7)
- ○ Library (8)
- ○ Magazines (9)
- ○ Newspapers (10)
- ○ Telephone information number (11)
- ○ Complimentary, alternative, or unconventional practitioner (12)
- ○ Other (please specify) (91) _____

Page Break

HINTS_A8 Have you ever looked for information about vaccines from any source?

- ○ Yes (1)
- ○ No (2)

End of Block: HISB - LOOKING FOR HEALTH INFORMATION

Start of Block: HISB - USING THE INTERNET TO FIND INFORMATION

HINTS_B1 Do you **EVER** go online to access the Internet or World Wide Web, or to send and receive e-mail?

- ○ Yes (1)
- ○ No (2)

Page Break

Display This Question:

If HINTS_B1 = Yes

HINTS_B2 When you use the Internet, do you access it through...

Display This Question:

If HINTS_B1 = Yes

HINTS_B2a A regular dial-up telephone line.

- Yes (1)
- No (2)

Display This Question:

If HINTS_B1 = Yes

HNTS_B2b Broadband such as DSL, cable, or FiOS.

- Yes (1)
- No (2)

Display This Question:

If HINTS_B1 = Yes

HINTS_B2c A cellular network (i.e., phone, 3G/4G).

- Yes (1)
- No (2)

Display This Question:

If HINTS_B1 = Yes

HINTS_B2d A wireless network (Wi-Fi).

- Yes (1)
- No (2)

Page Break

Display This Question:

If HINTS_B1 = Yes

HINTS_B3 In the **PAST 12 MONTHS**, have you used the Internet to look for information about vaccines for yourself?

- ○ Yes (1)
- ○ No (2)

Page Break

Display This Question:

If HINTS_B1 = Yes

HINTS_B4 How often do you access the Internet through each of the following?

Display This Question:

If HINTS_B1 = Yes

X→ X→

HINTS_B4a Computer at home.

- ○ Daily (1)
- ○ Sometimes (2)
- ○ Never (3)
- ○ Not Applicable (4)

Display This Question:

If HINTS_B1 = Yes

X→ X→

HINTS_B4b Computer at work.

- Daily (1)
- Sometimes (2)
- Never (3)
- Not Applicable (4)

Display This Question:

If HINTS_B1 = Yes

X→ X→

HINTS_B4c Computer in a public place (library, community center, other).

- Daily (1)
- Sometimes (2)
- Never (3)
- Not Applicable (4)

Display This Question:

If HINTS_B1 = Yes

X→ X→

HINTS_B4d On a mobile device (cell phone/smartphone/tablet).

- ○ Daily (1)
- ○ Sometimes (2)
- ○ Never (3)
- ○ Not Applicable (4)

Page Break

HINTS_B5 In the **PAST 12 MONTHS**, have you used a computer, smartphone, or other electronic means to do any of the following?

HINTS_B5a

Looked for health or medical information for yourself.

- ○ Yes (1)
- ○ No (2)

HINTS_B5b Bought medicine or vitamins online.

- ○ Yes (1)
- ○ No (2)

HINTS_B5c Used e-mail or the Internet to communicate with a doctor or doctor's office.

- Yes (1)
- No (2)

HINTS_B5d Tracked healthcare charges and costs.

- Yes (1)
- No (2)

HINTS_B5e Looked up medical test results.

- Yes (1)
- No (2)

HINTS_B5f Made appointments with a health care provider.

- Yes (1)
- No (2)

HINTS_B5g Looked for information about the side-effects of medicines or vaccines.

- ○ Yes (1)
- ○ No (2)

Page Break

HINTS_B6 Please indicate if you have each of the following. (Check all that apply.)

- ☐ Tablet computer (for example, an Apple iPad, Samsung Galaxy, Motorola Xoom, or Kindle Fire) (2)
- ☐ Smartphone (for example, an Apple iPhone, Android phone, Blackberry, or Windows phone) (3)
- ☐ Basic cell phone only (4)
- ☒ I do not have any of the above (5)

Page Break

Display This Question:

If HINTS_B6 = Tablet computer (for example, an Apple iPad, Samsung Galaxy, Motorola Xoom, or Kindle Fire)

Or HINTS_B6 = Smartphone (for example, an Apple iPhone, Android phone, Blackberry, or Windows phone)

X→ X→

HINTS_B7 On your tablet or smartphone, do you have any applications (also known as 'apps') related to health and wellness?

- ○ Yes (1)
- ○ No (2)
- ○ Don't know (3)

Display This Question:

If HINTS_B6 = Tablet computer (for example, an Apple iPad, Samsung Galaxy, Motorola Xoom, or Kindle Fire)

Or HINTS_B6 = Smartphone (for example, an Apple iPhone, Android phone, Blackberry, or Windows phone)

HINTS_B8 Has your tablet or smartphone...

Display This Question:

If HINTS_B6 = Tablet computer (for example, an Apple iPad, Samsung Galaxy, Motorola Xoom, or Kindle Fire)

Or HINTS_B6 = Smartphone (for example, an Apple iPhone, Android phone, Blackberry, or Windows phone)

X→ X→

HINTS_B8a Helped you track progress on a health-related goal such as quitting smoking, losing weight, or increasing physical activity?

- ○ Yes (1)
- ○ No (2)

Display This Question:

If HINTS_B6 = Tablet computer (for example, an Apple iPad, Samsung Galaxy, Motorola Xoom, or Kindle Fire)

Or HINTS_B6 = Smartphone (for example, an Apple iPhone, Android phone, Blackberry, or Windows phone)

X→ X→

HINTS_B8b Helped you make a decision about how to treat an illness or condition?

- ○ Yes (1)
- ○ No (2)

Display This Question:

If HINTS_B6 = Tablet computer (for example, an Apple iPad, Samsung Galaxy, Motorola Xoom, or Kindle Fire)

Or HINTS_B6 = Smartphone (for example, an Apple iPhone, Android phone, Blackberry, or Windows phone)

X→ X→

HINTS_B8c Helped you in dicussions with your health care provider?

- ○ Yes (1)
- ○ No (2)

Page Break

HINTS_B9 In the **PAST 12 MONTHS**, have you used an electronic wearable device to monitor or track your health or activity? For example, a FitBit, Apple iWatch, or Garmin Vivofit.

- Yes (1)
- No (2)

Display This Question:

If HINTS_B9 = Yes

HINTS_B10 In the past month, how often did you use a wearable device to track your health?

- Every day (1)
- Almost every day (2)
- 1-2 times per week (3)
- Less than once per week (4)
- I did not use a wearable device in the past month (5)

Display This Question:

If HINTS_B9 = Yes

HINTS_B11 Would you be willing to share health data from your wearable device with...

Display This Question:

If HINTS_B9 = Yes

X→ X→

HINTS_B11a Your health care provider.

- Yes (1)
- No (2)

Display This Question:

If HINTS_B9 = Yes

X→ X→

HINTS_B11b Your family and friends.

- Yes (1)
- No (2)

Page Break

HINTS_B12 In the **PAST 12 MONTHS**, have you used an electronic monitoring device to monitor or track your health? For example, a glucometer or digital blood pressure device.

- ○ Yes (1)
- ○ No (2)

HINTS_B13

Have you shared health information from either an electronic monitoring device or smartphone with a health professional within the **PAST 12 MONTHS**?

- ○ Yes (1)
- ○ No (2)

Page Break

HINTS_B14

Sometimes people use the Internet to connect with other people online through social networks like Facebook, Twitter, and Instagram. This is often called "social media".

In the **P**AST 12 MONTHS, have you used the Internet for any of the following reasons?

HINTS_B14a

To visit a social networking site, such as Facebook or LinkedIn.

- ○ Yes (1)
- ○ No (2)

HINTS_B14b

To share health information on social networking sites, such as Facebook, Twitter, or Instagram.

- ○ Yes (1)
- ○ No (2)

HINTS_B14c

To write in an online diary or blog (i.e., Web log).

- ○ Yes (1)
- ○ No (2)

HINTS_B14d

To participate in an online forum or support group for people with a similar health or medical issue.

- ○ Yes (1)
- ○ No (2)

HINTS_B14e

To watch a health-related video on YouTube or other online video streaming service.

- ○ Yes (1)
- ○ No (2)

Page Break

Q145 Have you sent or received a text message from a doctor or other health care professional within the **PAST 12 MONTHS**?

- Yes (1)
- No (2)
- Don't know (3)

End of Block: HISB - USING THE INTERNET TO FIND INFORMATION

Start of Block: HEALTH LITERACY - GENERAL (CHEW ITEMS)

HEALTHLIT

The following questions are about how you feel about your ability to understand health information.

CHEW1 How confident are you filling out medical forms by yourself?

- ○ Not at all (5)
- ○ A little bit (4)
- ○ Somewhat (3)
- ○ Quite a bit (2)
- ○ Extremely (1)
- ○ I don't know (88)

CHEW2 How often do you have problems learning about your medical condition because of difficulty understanding written information?

- ○ Never (5)
- ○ Occasionally (4)
- ○ Sometimes (3)
- ○ Often (2)
- ○ Always (1)
- ○ I don't know (88)

CHEW3 How often do you need to have someone help you when you read, pamphlets, or other written material from your doctor or pharmacy?

- ○ Never (1)
- ○ Occasionally (2)
- ○ Sometimes (3)
- ○ Often (4)
- ○ Always (5)
- ○ I don't know (88)

End of Block: HEALTH LITERACY - GENERAL (CHEW ITEMS)

Start of Block: HEALTH LITERACY - eHEALS

EHEALS

The following questions related to how you feel about your ability to use health information that you find or receive electronically, such as health information online through Internet sources.

EHEALS1 I know **what** health resources are available on the Internet.

- ○ Strongly Disagree (1)
- ○ Disagree (2)
- ○ Undecided (3)
- ○ Agree (4)
- ○ Strongly Agree (5)

EHEALS2 I know **where** to find helpful health resources on the Internet.

- ○ Strongly Disagree (1)
- ○ Disagree (2)
- ○ Undecided (3)
- ○ Agree (4)
- ○ Strongly Agree (5)

EHEALS3 I know **how** to find helpful health resources on the Internet.

- ○ Strongly Disagree (1)
- ○ Disagree (2)
- ○ Undecided (3)
- ○ Agree (4)
- ○ Strongly Agree (5)

X→ X→

EHEALS4 I know **how to use** the Internet to answer my questions about health.

- ○ Strongly Disagree (1)
- ○ Disagree (2)
- ○ Undecided (3)
- ○ Agree (4)
- ○ Strongly Agree (5)

X→ X→

EHEALS5 I know how to use **the health information** I find on the Internet to help me.

- ○ Strongly Disagree (1)
- ○ Disagree (2)
- ○ Undecided (3)
- ○ Agree (4)
- ○ Strongly Agree (5)

EHEALS6 I have the skills I need to **evaluate** the health resources I find on the Internet.

- ○ Strongly Disagree (1)
- ○ Disagree (2)
- ○ Undecided (3)
- ○ Agree (4)
- ○ Strongly Agree (5)

EHEALS7 I can tell **high quality** health resources from **low quality** health resources on the Internet.

- Strongly Disagree (1)
- Disagree (2)
- Undecided (3)
- Agree (4)
- Strongly Agree (5)

EHEALS8 I feel **confident** in using information from the Internet to make health decisions.

- Strongly Disagree (1)
- Disagree (2)
- Undecided (3)
- Agree (4)
- Strongly Agree (5)

Page Break

EHOPT1 How **useful** do you feel the Internet is in helping you in making decisions about your health?

- Not useful at all (1)
- Not useful (2)
- Unsure (3)
- Useful (4)
- Very useful (5)

EHOPT2 How **important** is it for you to be able to access health resources on the Internet?

- Not important at all (1)
- Not important (2)
- Unsure (3)
- Important (4)
- Very important (5)

End of Block: HEALTH LITERACY - eHEALS

Start of Block: SITUATION - BARRIERS TO CARE

SITUATION_BARRIERS

The following questions ask about any challenges you may have experienced obtaining health care.

NOS_SM6

What percent of your doctors or other health care providers do you think are aware of your sexual orientation (meaning they are aware of whether you consider yourself bisexual, gay, straight, etc.)?

- ○ 0% (0)
- ○ 10% (1)
- ○ 20% (2)
- ○ 30% (3)
- ○ 40% (4)
- ○ 50% (5)
- ○ 60% (6)
- ○ 70% (7)
- ○ 80% (8)
- ○ 90% (9)
- ○ 100% (19)

NOS_GM6

What percent of your doctors or other health care providers do you think are aware that you are a gender minority person (for example: genderqueer, non-binary, questioning one's gender identity, transgender, etc.)?

- 0% (0)
- 10% (1)
- 20% (2)
- 30% (3)
- 40% (4)
- 50% (5)
- 60% (6)
- 70% (7)
- 80% (8)
- 90% (9)
- 100% (19)
- Not applicable (I do not identify as a gender minority person) (20)

Page Break

DELAYCARE In the **PAST 12 MONTHS**, were you delayed in getting medical care, tests, or treatments that you or a healthcare provider believed necessary?

- Yes (1)
- No (0)

ANTMEDDISC

Was there a time in the **P**AST 12 MONTHS when you needed to see a health care provider but did not because you thought you would be disrespected or mistreated?

- Yes (1)
- No (0)

Display This Question:

If ANTMEDDISC = Yes

ANTMEDDISCY When you put off seeing a health care provider in the **PAST 12 MONTHS** because you thought you were going to be disrespected, were you concerned you would be disrespected or mistreated because of your ... (Check all that apply.)

- ☐ Ability/disability status (1)
- ☐ Age (2)
- ☐ Body size, weight, or shape (3)
- ☐ Gender expression (4)
- ☐ Gender identity (5)
- ☐ Race and/or ethnicity (6)
- ☐ Sexual orientation (7)
- ☐ Something else (please specify) (8) _____
- ☐ ⊗ None of the above (0)

End of Block: SITUATION - BARRIERS TO CARE

Start of Block: SITUATION - ACCESS TO CARE

SITUATION_ACCESS

The following questions help us to understand your access to health care.

PCP A primary care provider is a health care provider who takes care of your overall general health and may coordinate your care with other medical specialists. Do you have a primary care provider (PCP)?

- Yes (1)
- No (0)
- I don't know (88)

Display This Question:

If PCP = Yes

PCP_LASTYEAR Have you seen your primary care provider (PCP) in the **PAST 12 MONTHS**?

- Yes (1)
- No (0)
- I don't know (88)

TRANSDOC In the PAST 12 MONTHS have you gone to a doctor, health care provider or clinic for transgender-related health care, such as hormone treatment?

- ○ Yes (1)
- ○ No (0)
- ○ I don't know (88)

X→ X→

GAHORMONE_EVER Have you **EVER** taken hormones or medication for the purposes of gender affirmation (also called gender transition)?

- ○ Yes (1)
- ○ No (0)

Display This Question:

If GAHORMONE_EVER = Yes

X→ X→

GAHORMONE_AN Are you **CURRENTLY** taking hormones or medications for the purposes of gender affirmation (also called gender transition)?

- ○ Yes (1)
- ○ No (0)

Page Break

INSURANCE Are you **CURRENTLY** covered by any health insurance or health coverage plan?

- ○ Yes (1)
- ○ No (0)
- ○ I don't know (88)

Display This Question:

If INSURANCE = Yes

INSURANCE_TYPE Are you **CURRENTLY** covered by any of the following types of health insurance or health coverage plans? (If you have more than one insurance/coverage plans, please select your primary/coverage plan.)

- ○ Insurance through my current or former employer or union (1)
- ○ Insurance through someone else's current of former employer or union (2)
- ○ Insurance purchased through Healthcare.gov or another health insurance marketplace (sometimes called "Obamacare" or the Affordable Care Act") (3)
- ○ Insurance purchased directly through an insurance company (4)
- ○ Medicare (for people 65 and older or people with certain disabilities) (5)
- ○ Medicaid (government-assistance plan for those with low incomes or a disability) (6)
- ○ TRICARE or other military healthcare (7)
- ○ Veteran's Affairs (VA) (8)
- ○ Indian Health Service (9)
- ○ Other (please specify) (10) _____

End of Block: SITUATION - ACCESS TO CARE

Start of Block: SITUATION - PREVENTIVE CARE

SITUATION_PREVENTIVE

The following questions help us to understand what sorts of preventive care you may have received in the past.

PROMIS1 In general, would you say your health is…

- ○ Excellent (5)
- ○ Very good (4)
- ○ Good (3)
- ○ Fair (2)
- ○ Poor (1)

Page Break

HIVTEST_YEAR Have you been tested for HIV in the **P**AST 12 MONTHS?

- ○ Yes (1)
- ○ No (0)
- ○ I don't know (88)

HIVSTATUS What is your HIV status?

- ○ Positive (1)
- ○ Negative (0)
- ○ I don't know (I don't know whether or not I have HIV.) (88)

Page Break

VAX_EVER Other than the human papillomavirus (HPV) vaccine, have you received any other vaccines? For example, a vaccine for the flu, pneumonia (pneumococcal), hepatitis A/B, or shingles?

- ○ Yes (1)
- ○ No (0)
- ○ I don't know (88)

Display This Question:

If VAX_EVER = Yes

Income

How many preventive vaccines have you received since you were 18 years old?

- ○ 0 (0)
- ○ 1-2 (1)
- ○ 3 or more (2)
- ○ I don't know (88)

Page Break

PAP_EVER_V

Have you **EVER** had a Pap smear or Pap test? (A Pap smear or Pap test is a routine test in which a health care provider places an instrument inside the vagina, examines the cervix, and takes a few cells from the cervix with a small stick or brush to look for abnormal or cancer cells.)

- ○ Yes (1)
- ○ No (0)
- ○ I don't have a cervix (2)
- ○ I don't know (88)

Display This Question:

If PAP_EVER_V = Yes

HPV_EVER An HPV test is sometimes added to the Pap test for cervical cancer screening. Have you **EVER** had an HPV test with along with your cervical Pap test?

- ○ Yes (1)
- ○ No (0)
- ○ I don't know (88)

ANORECTCA_SCREEN) Have you **EVER** had any of the following tests as an evaluation for anal or rectal cancer? (Check all that apply)

☐ Digital anal rectal exam (an examination where a doctor or health care provider inserts their finger into your anus (butt) (1)

☐ Anal HPV test (a routine test with a swab that tests for human papillomavirus, HPV) (2)

☐ Anal Pap smear (a routine test in which a healthcare provider takes a few cells from the anus (butt) using a swab for abnormal or cancer cells) (3)

☐ High-Resolution Anoscopy (HRA) (an exam with a microscope of the rectum and anus/butt) (4)

☐ ⊗ None of these (5)

☐ ⊗ I don't know (88)

End of Block: SITUATION - PREVENTIVE CARE

Start of Block: DEMOGRAPHICS - SOGI

DEMO_SOGI

The following questions help us to have the most updated demographic information about you. You may have answered these questions in the The PRIDE Study Annual Questionnaire. We appreciate you providing your latest information.

ORIENTATION What is your current sexual orientation? (Check all that apply.)

- ☐ Asexual (1)
- ☐ Bisexual (2)
- ☐ Gay (3)
- ☐ Lesbian (4)
- ☐ Pansexual (5)
- ☐ Queer (6)
- ☐ Questioning (7)
- ☐ Same-gender loving (8)
- ☐ Straight/Heterosexual (9)
- ☐ Two-spirit (10)
- ☐ Another sexual orientation (please specify) (11) _____

GENDERID What is your current gender identity? (Check all that apply.)

- ☐ Genderqueer (1)
- ☐ Man (2)
- ☐ Transgender man (3)
- ☐ Transgender woman (4)
- ☐ Woman (5)
- ☐ Another gender identity (please specify) (6) _____

LIVEGEN What gender do you live as your day-to-day life?

- ○ Man (1)
- ○ Woman (2)
- ○ Sometimes man, sometimes woman (3)
- ○ Third gender other than man or woman (4)

SAAB What was your sex assigned at birth, for example on your original birth certificate?

- ○ Male (1)
- ○ Female (2)

X→ X→

INTERSEX_DEF Do you identify as intersex?

- ○ Yes (1)
- ○ No (0)

End of Block: DEMOGRAPHICS - SOGI

Start of Block: DEMOGRAPHICS - ORGANS

DEMO_ORGANS

To understand your health, we need to know what organs you were born with.

Note: People may have a wide range of language or terms for their physical anatomy. Some people are not comfortable with the term ‘vagina’ and may prefer the term ‘frontal genital opening.’ The PRIDE Study chooses to include both the terms ‘vagina’ and ‘frontal genital opening’ for all relevant questions to honor the preferences and comfort of our participants.

ORGANS_BORN Which of the following organs were you born with? (Check all that apply.)

- [ ] Cervix (you likely have/had this if you were assigned female sex at birth) (1)
- [ ] Ovaries (2)
- [ ] Penis/Phallus (not including a prosthetic) (3)
- [ ] Prostate (you likely have this if you were assigned male sex at birth) (4)
- [ ] Testicles (5)
- [ ] Uterus/Womb (6)
- [ ] Vagina/Frontal genital opening (7)

ORGANS_NOW Which of the following organs do you have now? (Check all that apply.)

- ☐ Breasts or breast tissue (1)
- ☐ Cervix (you likely have this if you have a uterus or womb) (2)
- ☐ Ovaries (3)
- ☐ Penis/Phallus (not including a prosthetic) (4)
- ☐ Prostate (you likely have this if you were assigned male sex at birth) (5)
- ☐ Testicles (6)
- ☐ Uterus/Womb (7)
- ☐ Vagina/Frontal genital opening (8)

End of Block: DEMOGRAPHICS - ORGANS

Start of Block: DEMOGRAPHICS - RACE/MARITAL/AGE/WORK/INCOME/EDUC

DEMO_FINAL

Thank you for your patience, you're almost done. Please answer these final demographic questions.

RACE_ETHN Which categories describe you? (Check all that apply.)

☐ American Indian or Alaska Native (For example: Aztec, Blackfeet Tribe, Mayan, Navajo Nation, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, etc.) (1)

☐ Asian (For example: Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, etc.) (2)

☐ Black, African American or African (For example: African American, Ethiopian, Haitian, Jamaican, Nigerian, Somali, etc.) (3)

☐ Hispanic, Latino or Spanish (For example: Columbian, Cuban, Dominican, Mexican or Mexican American, Puerto Rican, Salvadoran, etc.) (4)

☐ Middle Eastern or North African (For example: Algerian, Egyptian, Iranian, Lebanese, Moroccan, Syrian, etc.) (5)

☐ Native Hawaiian or other Pacific Islander (For example: Chamorro, Fijian, Marshallese, Native Hawaiian, Tongan, etc.) (6)

☐ White (For example: English, European, French, German, Irish, Italian, Polish, etc.) (7)

☐ ⊗None of these fully describe me. (please specify) (8)
_____

Page Break

RELATIONSHIP Are you **CURRENTLY** in a relationship?

- ○ Yes (1)
- ○ No (0)

MARITALSTATUS What is your **CURRENT** legal marital status?

- ○ Married (1)
- ○ Legally recognized civil union (2)
- ○ Registered domestic partnership (3)
- ○ Widowed (4)
- ○ Divorced (5)
- ○ Separated (6)
- ○ Single, never married (7)

AGE Enter your age in years (using whole numbers).

_____

WORK Do you **CURRENTLY** work one or more paid jobs?

- ○ Yes (1)
- ○ No (0)

OCC Which of the following describes your current occupation?

- ○ Employed, working 40 or more hours per week (1)
- ○ Employed, working 1-39 hours per week (2)
- ○ Temporarily employed (3)
- ○ Self-employed (4)
- ○ Not employed, looking for work (5)
- ○ Not employed, not looking for work (6)
- ○ Homemaker (7)
- ○ Student (Full time) (8)
- ○ Student (Part time) (9)
- ○ Disabled, not able to work (10)
- ○ Retired (11)

X→ X→

INCOME What were your individual earnings (in US Dollars) before taxes and deductions from ALL sources (including jobs, businesses, welfare, child support, disability, social security, etc.) in the 2019 tax year?

- ○ $0 (1)
- ○ $1 - 10,000 (2)
- ○ $10,001 - 20,000 (3)
- ○ $20,001 - 30,000 (4)
- ○ $30,001 - 40,000 (5)
- ○ $40,001 - 50,000 (6)
- ○ $50,001 - 60,000 (7)
- ○ $60,001 - 70,000 (8)
- ○ $70,001 - 80,000 (9)
- ○ $80,001 - 90,000 (10)
- ○ $90,001 - 100,000 (11)
- ○ $100,001+ (12)

Page Break

ED_LEVEL What is your highest education level completed?

- ○ No schooling (1)
- ○ Nursery school to high school, no diploma (2)
- ○ High school graduate or equivalent (3)
- ○ Trade/Technical/Vocational training (4)
- ○ Some college (5)
- ○ 2-year college degree (6)
- ○ 4-year college degree (7)
- ○ Master's degree (8)
- ○ Doctoral degree (9)
- ○ Professional degree (e.g., M.D., J.D., M.B.A.) (10)

Page Break

DEMO_CLOSE

YOU ARE <u>ALMOST DONE</u> WITH THIS SURVEY - PLEASE READ BELOW AND THEN CLICK NEXT

This is required in order for the system to mark your survey as "Complete."

Thank you for completing the **<u>HPV and Health Information Seeking Survey</u>**.

We deeply appreciate for your time, your interest in The PRIDE Study, and your investment in research that will help our communities understand how the experience of being LGBTQ+ is related to all aspects of health and life.

TO LOG YOUR SURVEY AS COMPLETE, PLEASE ADVANCE TO THE NEXT SCREEN

and then select "Back to Dashboard"

End of Block: DEMOGRAPHICS - RACE/MARITAL/AGE/WORK/INCOME/EDUC