

## Research and Applications

# Online health information seeking, health literacy, and human papillomavirus vaccination among transgender and gender-diverse people

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### ABSTRACT

**Objective:** The purpose of this study is to describe online health information seeking among a sample of transgender and gender diverse (TGD) people compared with cisgender sexual minority people to explore associations with human papillomavirus (HPV) vaccination, and whether general health literacy and eHealth literacy moderate this relationship.

**Materials and Methods:** We performed a cross-sectional online survey of TGD and cisgender sexual minority participants from The PRIDE Study, a longitudinal, U.S.-based, national health study of sexual and gender minority people. We employed multivariable logistic regression to model the association of online health information seeking and HPV vaccination.

**Results:** The online survey yielded 3258 responses. Compared with cisgender sexual minority participants, TGD had increased odds of reporting HPV vaccination (aOR, 1.5; 95% CI, 1.1-2.2) but decreased odds when they had looked for information about vaccines online (aOR, 0.7; 95% CI, 0.5-0.9). TGD participants had over twice the odds of reporting HPV vaccination if they visited a social networking site like Facebook (aOR, 2.4; 95% CI, 1.1-5.6). No moderating effects from general or eHealth literacy were observed.

**Discussion:** Decreased reporting of HPV vaccination among TGD people after searching for vaccine information online suggests vaccine hesitancy, which may potentially be related to the quality of online content. Increased reporting of vaccination after using social media may be related to peer validation.

**Conclusions:** Future studies should investigate potential deterrents to HPV vaccination in online health information to enhance its effectiveness and further explore which aspects of social media might increase vaccine uptake among TGD people.

**Key words:** health literacy, information seeking behavior, papillomavirus vaccines, sexual and gender minorities, transgender persons

## INTRODUCTION

### Background

Individuals who encounter cultural barriers to accessing care may be more likely to seek health information online.<sup>1</sup> Data from the Health Information National Trends Survey have found that presumably cisgender sexual minority people (eg, lesbian women, gay men, bisexual men and women) are more likely to seek and be exposed to incidental health information online, more likely to watch online health-related videos on YouTube, and less likely to first seek health information from a physician compared with their heterosexual peers.<sup>2–4</sup> Less is known about online health information seeking among transgender and gender diverse (TGD) people who are estimated to number at least 1.4 million in the United States.<sup>5</sup> TGD people have gender identities or gender expressions that may not align with those commonly associated with their sex assigned at birth and may identify as transgender men, transgender women, trans men, trans women, men, women, or other gender identities.<sup>6,7</sup> Cisgender people have gender identities or gender expressions that align with those commonly associated with their sex assigned at birth. From an informatics perspective, the availability of datasets that capture detailed information about gender identity to accurately represent TGD people have been limited.<sup>8</sup> Accordingly, the collection of national data on TGD populations was declared a priority objective for U.S. public health infrastructure in Healthy People 2030.<sup>9</sup>

TGD people may have unique health information needs relating to supporting gender affirmation such as gender-affirming hormone therapy, which may motivate them to seek health information online.<sup>10</sup> In addition, TGD people utilize the Internet for community building and information sharing.<sup>11</sup> However, there is a paucity of research that explores how online health information seeking among TGD people may be associated with personal health decision-making, like whether or not to receive a vaccine. Moreover, eHealth literacy—the ability to use electronic health information to make health decisions—has been explored in presumably cisgender sexual minority people but not among TGD people.<sup>12</sup>

Human papillomavirus (HPV), the most common sexually-transmitted infection (STI) in the United States, is known to cause 90% of cervical and anal cancers; 70% of oropharyngeal, vaginal, and vulvar cancers; 60% of penile cancers; and is largely preventable by vaccination.<sup>13–15</sup> Few studies have focused on HPV vaccination among TGD people even though these communities are at increased risk for HPV infection compared with the general population.<sup>16,17</sup>

### Objective

The purpose of this study is to describe online health information seeking among a sample of TGD people compared with cisgender sexual minority people to explore associations with HPV vaccination, and whether general health literacy and eHealth literacy moderate this relationship.

## MATERIALS AND METHODS

### Theoretical framework

We adapted the Integrative Model of eHealth Use (IMeHU) to guide our study.<sup>18</sup> IMeHU posits that online health information seeking is associated with health behavior outcomes, and this relationship is influenced by individual factors, such as general health literacy, eHealth literacy, Internet use, health knowledge, situation factors (eg, access to care, preventative care, barriers to care), and demographics (Figure 1).

### Study design and sample

We employed a cross-sectional design to explore the association of online health information seeking and HPV vaccination among TGD and cisgender sexual minority people. Between February and May 2020, we launched an online survey to an existing research-ready cohort. E-mail and text message invitations to participate were sent to 17 036 participants in The Population Research in Identity and Disparities for Equality (PRIDE) Study ([pridestudy.org](http://pridestudy.org)), a longitudinal, U.S.-based, national health study of sexual and gender minority people.<sup>19</sup> The PRIDE Study launched in 2017 and recruits adults aged 18-years and older, who are English speaking, and reside in the United States or its territories, who self-identify as a sexual and/or gender minority person. Details of The PRIDE Study longitudinal cohort, its digital health research platform, and dataset are described elsewhere.<sup>20,21</sup> Participants who completed the survey were entered in a drawing to win 1 of 10 \$50 gift cards. This study was approved by the Institutional Review Boards at Columbia Irving University Medical Center (IRB-AAAS6733) and Stanford University Medical School (IRB-48707).

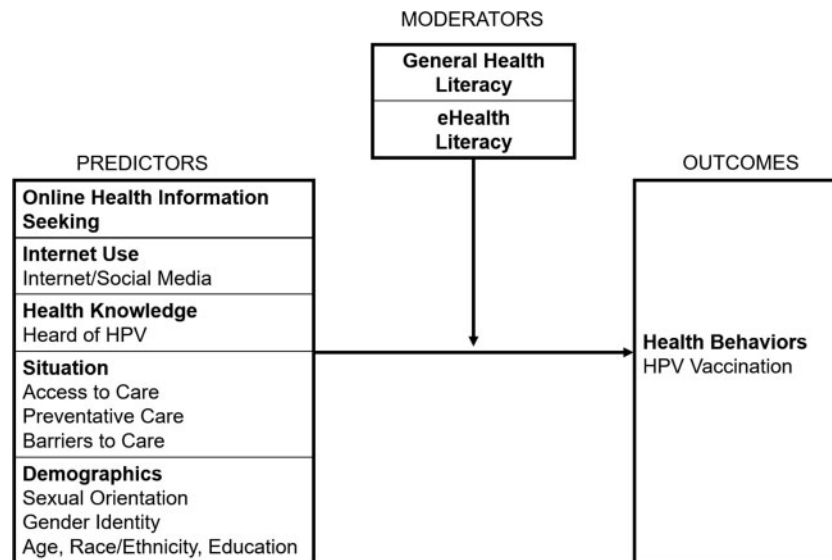
### Survey administration

Data were collected using Qualtrics (Qualtrics, Provo, UT), and the survey was hosted on The PRIDE Study Web-based participant portal.<sup>20</sup> We used a modified Dillman<sup>22</sup> method for survey reminders that were issued by The PRIDE Study web portal via email and opt-in text message.

### Measures

#### Online health information seeking and Internet use

We used 23-items from the Health Information National Trends Survey (HINTS)<sup>23</sup> to assess preferences for online health information seeking and Internet use (Supplementary Appendix A). HINTS is an instrument administered by the National Cancer Institute to understand how adults obtain health information. By using HINTS items, we sought to better understand preferences for information seeking, especially among TGD people, as these communities were not recruited in previous administrations of HINTS. We assessed the primary independent variables of interest—online health information seeking related to vaccines and general online health information seeking—using 2 HINTS (Version 5 Cycle 3) items: HINTS\_B3) In the past 12 months, have you used the Internet to look for information about vaccines for yourself?; and 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. Several HINTS items



**Figure 1.** Adapted Integrative Model of eHealth Use (IMeHU) Predictors are factors related to health behavior outcomes and additional factors moderate this relationship.

were modified from their originally validated form in order to include language related to vaccines instead of the original language that referred to cancer.

#### General health literacy

We assessed general health literacy using 3 discrete subjective items proposed in the health literacy literature.<sup>24</sup> These items were validated as a brief alternative to longer format instruments that address reading and understanding of written health information. The 3 Likert response items addressed confidence in filling out forms, difficulty understanding written communication, and needing help to read written material from a doctor or pharmacy.

#### eHealth literacy

We assessed eHealth literacy using the Electronic Health Literacy Scale (eHEALS),<sup>25</sup> an 8-item scale that uses Likert responses to yield a total score of 8 to 40 (low to high); corresponding with self-perceived eHealth literacy in 6 domains; traditional literacy, health literacy, information literacy, scientific literacy, media literacy, and computer literacy. eHEALS has been validated in numerous settings and populations including presumably cisgender sexual minority people, such as men who have sex with men.<sup>12,25</sup>

#### HPV knowledge, HPV vaccination

Access to Care, Preventative Care, Barriers to Care

#### Demographic characteristics

We assessed HPV knowledge, HPV vaccination, access to care, preventative care, barriers to care, and demographic characteristics using items taken from The PRIDE Study Annual Questionnaire 2018. Although previously administered, the items in our survey were posed again to ensure contemporaneous accuracy with other items in the cross-sectional survey. The PRIDE Study Annual Questionnaire 2018 is publicly available for review and use at [pridestudy.org/collaborate](http://pridestudy.org/collaborate). Our final survey included 74 items and could be completed in 15 to 20 minutes (Supplementary Appendix A). Participants could skip any item and pause and resume the survey during

the study period by logging into their existing web portal accounts with The PRIDE Study.

#### Classification of TGD and cisgender participants

Self-reported *gender identity* and *sex assigned at birth* distinguished TGD participants from cisgender participants; Boolean logic accounted for multiple responses to *gender identity*. We categorized participants as TGD if they indicated their *gender identity* was woman or transgender woman, and their *sex assigned at birth* was male; if they indicated their *gender identity* was man or transgender man, and their *sex assigned at birth* was female; or if they indicated their *gender identity* was genderqueer, another gender identity, transgender man, or transgender woman. Participants were categorized as cisgender if they indicated their *sex assigned at birth* was male and their *gender identity* was man; or if they indicated their *sex assigned at birth* was female and their *gender identity* was woman. We excluded individuals who did not report their *sex assigned at birth*.

#### Statistical analysis

Analyses were performed in SAS 9.4 (SAS Institute Inc., Cary, NC). Descriptive statistics for demographics were calculated, including means with standard deviations. Pearson's Chi-squared test, Fisher's Exact test, and paired t-tests were employed to examine differences in categorical and continuous variables (eg, eHEALS scores). Alpha was set at .001 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. We used variance inflation factor (VIF) statistics to assess for multicollinearity. A VIF value less than 5 suggested no multicollinearity.<sup>26</sup> We used multivariable logistic regression to model the association of health information seeking on HPV vaccination. TGD were compared with cisgender participants as the reference group. We performed *post hoc* testing using the Bonferroni-Holm sequential procedure for adjusted alphas.<sup>27</sup> To test for any moderating effects, we ran a separate model for each interaction term; including each of the 3 categorical general health literacy variables and the

eHEALS score variable. We evaluated the effect of each of the interaction terms on the logistic regression models using likelihood ratio tests.

## RESULTS

There were 3339 completed responses (eg, viewed every question and arrived at the survey completion page). We excluded 81 (2.4%) of the responses due to missing sex assigned at birth, gender identity, or age. Of the remaining 3258 participants, 1172 (36%) were classified as TGD and 2086 (64%) as cisgender (Table 1). The median age of participants was 31 years (interquartile range [IQR] 25-43). TGD participants were slightly younger than cisgender participants ( $P < .0001$ ). A greater proportion of TGD participants were female sex assigned at birth (79.4%) compared with cisgender participants (56.1%,  $P < .0001$ ). Just over a third of TGD participants (35.8%) indicated their lived gender day-to-day was sometimes man, sometimes woman, or third gender other than man or woman. The proportion of white participants was slightly less for TGD participants (81.6%) compared with cisgender participants (82.5%,  $P < .0001$ ). The proportion of TGD participants of Black, African American or African race (1.0%) was less than half of cisgender participants (2.3%,  $P < .0001$ ). Similarly, the proportion of TGD participants of Hispanic, Latino, or Spanish ethnicity (1.3%) was less than half of cisgender participants (2.8%,  $P < .0001$ ). The proportion of TGD participants who had more than a high school education (92.7%), was slightly less than cisgender participants (95.5%,  $P < .0001$ ). All participants who identified as intersex (1.8%) answered the sex assigned at birth and gender identity questions and were thus classified as either TGD or cisgender. A greater proportion of TGD participants identified as intersex (2.3%) than cisgender participants (0.5%,  $P < .0001$ ).

### Online health information seeking and internet use

The groups had similar online health information seeking behavior and Internet use (Table 2). Nearly all participants used a computer, smartphone, or other electronic device to look for health or medical information in the past 12 months. Just under a third (31.4%) of TGD participants and 33.7% of cisgender participants used the Internet to look for information about vaccines in the past 12 months ( $P = .1704$ ). Nearly all participants (96.4%) visited a social networking site, like Facebook, in the past 12 months.

### General health literacy and eHealth literacy

In terms of the 3 discrete general health literacy items, 96.5% of TGD participants and 92.1% of cisgender participants reported they were “quite a bit” or “extremely confident” filling out medical forms by themselves ( $P < .0001$ , Table 2). Additionally, 88.9% of TGD participants and 94.1% of cisgender participants said they “never” or “occasionally” had difficulty understanding written communication ( $P < .0001$ ). Moreover, 95.1% of TGD participants and 98.1% of cisgender participants said they “never” or “occasionally” needed help to read written material from the doctor or pharmacy ( $P < .0001$ ). TGD participants’ self-perceived eHealth literacy measured by their eHEALS score (mean 31.7,  $SD$  11.6) was lower than cisgender participants’ eHEALS score (mean 38.2,  $SD$  14.9,  $P < .0001$ ).

### HPV knowledge and HPV vaccination

Nearly all (93.7%) participants had heard of HPV. A greater proportion of TGD participants (55.8%) reported HPV vaccination compared with cisgender participants (41.9%,  $P < .0001$ , Table 3). A smaller proportion of TGD participants (2.8%) than cisgender participants (3.7%) reported that a doctor refused to give them the HPV vaccine when they requested it ( $P < .0001$ ).

### Access to care, preventative care, barriers to care

In terms of access to care, the majority of all participants (84.3%) reported having a primary care provider (PCP) (Table 3). Nearly all participants (95.6%) had health insurance, but a smaller proportion of TGD participants (4.0%) had Medicaid insurance than cisgender participants (7.8%,  $P < .0001$ ). With regards to preventative care, a smaller proportion of TGD participants (76%) reported receiving 3 or more vaccines since 18 years of age than cisgender participants (83.3%,  $P < .0001$ ). Considering barriers to care, over 43% of TGD participants reported delaying necessary medical care in the past year compared with 24.5% of cisgender participants ( $P < .0001$ ).

### Modeling online health information seeking and HPV vaccination

To explore the relationship between health information seeking and HPV vaccination, we performed multivariable logistic regression. In our sample of 3258 participants, 1528 (46.9%) reported HPV vaccination. We performed a bivariate analysis of 30 predictors on the outcome HPV vaccination (not shown). Predictors that did not meet our entry criterion of  $P < .25$  were removed and were not proposed in the preliminary main effects model. Predictors were selected based on the IMeHU categories (ie, online health information seeking, Internet use, health knowledge, access to care, preventative care, barriers to care, and demographics). We summarize the reduced model in Table 4. Some variables were kept in the model even though they did not meet the entry criterion because they were important variables of interest (eg, online health information seeking). We performed a *post hoc* Bonferroni-Holm correction for multiple comparisons on the final reduced model.

### Predictors: Online health information seeking and internet use

After controlling for covariates including age, race/ethnicity, and education, we found that, compared with cisgender participants, TGD participants had decreased odds of reporting HPV vaccination when they looked for information on vaccines in the past 12 months (aOR, 0.7; 95% CI, 0.5-0.9) but over twice the odds of reporting HPV vaccination if they visited a social networking site like Facebook in the past 12 months (aOR, 2.4; 95% CI, 1.1-5.6). TGD participants had decreased odds of reporting HPV vaccination if they used a computer, smartphone, or other electronic means to track healthcare charges and costs (aOR, 0.6; 95% CI, 0.5-0.9) or to make appointments with a healthcare provider (aOR, 0.5; 95% CI, 0.4-0.9).

### Predictor: HPV knowledge

Compared with cisgender participants, TGD participants had over twice the odds of reporting HPV vaccination if they had heard of HPV (aOR, 2.1; 95% CI, 1.1-4.1).

**Table 1.** Participant characteristics among a sample of TGD and cisgender sexual minority participants in The PRIDE Study in the United States (N = 3258)

Characteristic	Total		TGD		Cisgender		<i>t</i> Test	<i>P</i> Value
	Mean	SD	Mean	SD	Mean	SD		
Age <sup>a</sup>	35.9	14.2	31.7	11.6	38.2	14.9	3256	<.0001
	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)	$\chi^2$	<i>P</i> Value
Sample	3258	(100)	1172	(36)	2086	(64)	256.4	<.0001
Sexual orientation <sup>b</sup>								
Asexual	89	(2.7)	51	(4.4)	38	(1.8)	622.0	<.0001
Bisexual	333	(10.2)	110	(9.4)	223	(10.7)		
Gay	765	(23.5)	48	(4.1)	717	(34.4)		
Lesbian	354	(10.9)	71	(6.1)	283	(13.6)		
Pansexual	106	(3.3)	66	(5.6)	40	(1.9)		
Queer	261	(8.0)	177	(15.1)	84	(4.0)		
Questioning	1	(0.03)	0	(0)	1	(0.1)		
Same-gender loving	5	(0.2)	3	(0.3)	2	(0.1)		
Straight/heterosexual	29	(0.9)	28	(2.4)	1	(0.1)		
Two-spirit	3	(0.1)	3	(0.3)	0	(0)		
Another sexual orientation	45	(1.4)	27	(2.3)	18	(0.9)		
>1 sexual orientation selected	1267	(39.0)	588	(50.6)	679	(32.6)		
Gender identity <sup>b</sup>								
Genderqueer	259	(8.0)	259	(22.1)	0	(0)	2666.7	<.0001
Man	908	(27.9)	18	(1.5)	890	(42.7)		
Transgender man	246	(7.6)	246	(21.0)	0	(0)		
Transgender woman	90	(2.8)	90	(7.7)	0	(0)		
Woman	1107	(34.0)	29	(2.5)	1078	(51.7)		
Another gender identity	252	(7.8)	237	(20.2)	15	(0.7)		
>1 gender identity selected	396	(12.2)	293	(25.0)	103	(4.9)		
Lived gender day to day								
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 <sup>b</sup>	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)		
Sex assigned at birth								
Female	2102	(64.5)	931	(79.4)	1171	(56.1)	178.0	<.0001
Male	1156	(35.5)	241	(20.6)	915	(43.9)		
Intersex <sup>c</sup>	81	(1.8%)	50	(2.3)	10	(0.5)	–	<.0001
Race/ethnicity <sup>b</sup>								
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	(0)		
White	2676	(82.1)	955	(81.6)	1721	(82.5)		
Other (none fully describe me)	41	(1.3)	21	(1.8)	20	(1.0)		
>1 race/ethnicity selected	312	(9.6)	136	(11.6)	176	(8.4)		
Education								
High school, trade, technical, vocational or less	181	(5.6)	87	(7.4)	94	(4.5)	132.7	<.0001
Some college, 2-y degree	688	(21.1)	346	(29.6)	342	(16.4)		
4-y college degree	1156	(35.5)	422	(36.0)	734	35.2)		
Master's degree or higher	1233	(37.9)	317	(27.1)	916	(43.9)		

TGD: transgender and gender diverse.

<sup>a</sup>Median age 31 (interquartile range, 25-43) years.<sup>b</sup>Categories may add up to more than 100% for select all that apply items.<sup>c</sup>Fisher's exact test for cell sizes < 30.**Predictors: Access to care, preventative care, barriers to care**

Having Medicaid insurance was associated with decreased odds of reporting HPV vaccination (aOR, 0.3; 95% CI, 0.1-0.7). Con-

versely, TGD participants who reported receipt of 3 or more vaccines since 18 years of age had 3.5 times the odds of reporting HPV vaccination compared with cisgender participants (aOR, 3.5; 95% CI, 1.5-8.2). Having had an HIV test in the past 12 months was as-

**Table 2.** Online health information seeking, Internet use, and health literacy among a sample of TGD and cisgender sexual minority participants in The PRIDE Study in the United States (N = 3258)

	Total		TGD		Cisgender		$\chi$	P Value
	n	%	n	%	n	%		
Online health information seeking								
In the past 12 months, have you used a computer, smartphone, or other electronic means to look for health of medical information for yourself?	3170	(97.3)	1153	(98.4)	2017	(96.7)	8.1	.0044
In the past 12 months, have you used the Internet to look for information about vaccines for yourself?	1068	(32.9)	366	(31.4)	702	(33.7)	1.9	.1704
Internet use								
In the past 12 months, used a computer, smartphone, or other electronic means to . . .								
Visit social networking site	3141	(96.4)	1128	(96.3)	2013	(96.5)	0.1407	.7076
Track healthcare charges and costs	2303	(70.8)	859	(73.5)	1444	(69.3)	6.6	.0105
Make appointments with a healthcare provider	2555	(78.5)	931	(79.6)	1624	(77.9)	1.4	.2335
Use e-mail or Internet to communicate with doctor	2701	(83.0)	1009	(86.2)	1692	(81.2)	13.0	.0003
Watch a health-related video online	1722	(52.9)	704	(60.1)	1018	(48.8)	38.6	<.0001
Buy medications or vitamins online	1448	(44.5)	492	(42.0)	956	(45.9)	4.6	.0319
Write in online diary or blog	561	(17.2)	288	(24.6)	273	(13.1)	69.3	<.0001
General health literacy								
How confident are you filling out medical forms by yourself?								
Not at all	14	(0.4)	9	(0.8)	5	(0.2)	—	<.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	1955	(60.3)	588	(50.4)	1367	(65.9)		
How often have problems difficulty understanding written communication? <sup>+</sup>								
Never	2330	(71.9)	753	(64.5)	1577	(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? <sup>a</sup>								
Never	2840	(87.4)	971	(83.3)	1869	(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)		
	Mean	SD	Mean	SD	Mean	SD	t test	P value
E-health literacy								
eHEALS score	35.9	14.2	31.7	11.6	38.2	14.9	3256	<.0001

eHEALS: Electronic Health Literacy Scale; TGD: transgender and gender diverse.

<sup>a</sup>Fisher's exact test for cell sizes <30.

sociated with increased odds of reporting HPV vaccination (aOR, 2.0; 95% CI, 1.5-2.8). However, having had an anorectal cancer screening was associated with decreased odds of vaccination (aOR, 0.6; 95% CI, 0.4-0.8). TGD participants who had delayed medical care in the past 12 months had 1.5 times the odds of reporting HPV vaccination compared with cisgender participants (aOR, 1.5; 95% CI, 1.1-2.0). Having less than 50% of healthcare providers be aware of participants' sexual orientation or gender identity was significant in preliminary logistic regression modeling, but was not associated with reporting HPV vaccination in the reduced model.

### Predictors: Demographics

Overall, TGD participants had 1.5 times the odds of reporting HPV vaccination compared with cisgender participants (aOR, 1.5; 95%

CI 1.1-2.2). TGD participants younger than 27-years-old had decreased odds of reporting HPV vaccination (aOR, 0.08; 95% CI, 0.05-0.11) than cisgender participants in the same age group. Race/ethnicity and education were not significant in the reduced model.

### Interaction of general health literacy and eHealth literacy

To test for moderation effects, we assessed for the interaction of general health literacy and eHealth literacy and online health information seeking. We added interaction terms 1 at a time to the logistic regression model for each of the 3 general health literacy variables and eHEALS score. We found no interaction of general health literacy or eHealth literacy with online health information seeking and HPV vaccination.



**Table 3.** HPV knowledge, HPV vaccination, access to care, preventative care, and barriers to care among a sample of TGD and cisgender sexual minority participants in The PRIDE Study in the United States (N = 3258)

	Total		TGD		Cisgender		$\chi$	P Value
	n	(%)	n	(%)	n	(%)		
HPV knowledge								
Ever heard of HPV?								
Yes	3053	(93.7)	1107	(94.5)	1946	(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)		
HPV vaccination								
Ever received HPV vaccine? (any doses)								
Yes	1528	(46.9)	654	(55.8)	874	(41.9)	70.3	<.0001
No	1446	(44.4)	412	(35.2)	1034	(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)		
Access to care								
Have a PCP	2709	(84.3)	944	(82.0)	1765	(85.6)	7.2	.0074
Have insurance	3103	(95.6)	1096	(94.2)	2007	(96.4)	8.3	.0039
Have Medicaid insurance	210	(6.5)	47	(4.0)	163	(7.8)	18.0	<.0001
Preventative care								
Number of vaccines received since 18-years old								
3 or more vaccines	2531	(80.7)	847	(76.0)	1684	(83.3)	25.9	<.0001
1-2 vaccines	287	(9.2)	125	(11.2)	162	(8.0)		
None	82	(2.6)	32	(2.9)	50	(2.5)		
I don't know	236	(7.5)	110	(9.9)	126	(6.2)		
Had HIV test in past 12 mo	1219	(38.0)	438	(38.2)	781	(37.9)	0.04	.8474
Had anorectal cancer screening	907	(28.7)	214	(19.0)	693	(34.1)	81.3	<.0001
Barriers to care								
Delayed medical care in past 12 mo								
≤50% healthcare providers aware of your sexual orientation	942	(28.1)	373	(31.8)	569	(27.3)	7.6	.0060
≤50% healthcare providers aware of your gender identity	584	(39.4)	378	(32.5)	206	(64.6)	107.6	<.0001

HIV: human immunodeficiency virus; HPV: human papillomavirus; PCP: primary care provider; TGD: transgender and gender diverse.

## DISCUSSION

Our study found that, in a sample of 3258 TGD and cisgender sexual minority people participating in The PRIDE Study, TGD people overall reported increased HPV vaccination compared with cisgender sexual minority people, but decreased vaccination after they used the Internet to search for information about vaccines. Decreased HPV vaccination after searching for vaccine information online may reflect concerns about the safety, efficacy, or necessity of vaccines manifested as vaccine hesitancy;<sup>28</sup> the delaying or refusal of vaccination that may be context-specific and related to factors like complacency, convenience, and confidence.<sup>29</sup> The quality of information that individuals encounter when searching for vaccine-specific information may also influence personal health decision-making surrounding vaccines, especially if the quality of the content is poor, or the content increases anxiety from misinformation. Anti-vaccine web content, even some specific to the HPV vaccine, has proliferated in recent years, and pro-HPV vaccine YouTube videos were 4 times more likely to report accurate information than anti-vaccine videos.<sup>30</sup> Moreover, online content that is not transgender-inclusive and affirming may pose an additional barrier to HPV vaccination among TGD people if they feel they vaccine is not appropriate for them.<sup>31</sup>

Conversely, our finding that visiting social networking sites, like Facebook, increased HPV vaccination among TGD participants is notable, given the ubiquity and widespread use of social media

today. Moreover, the prevalence of health information seeking on social media is increasing with peer interactions and the need for social and emotional support contributing to social media use.<sup>32</sup> In the era of COVID-19, social media can negatively and positively affect health information related to vaccines. On the one hand, social media facilitates the spread of misinformation that further contributes to vaccine hesitancy; on the other hand, social media is used to promote information accuracy campaigns to counteract vaccine misinformation.<sup>33</sup>

Peer norms are a facilitator for preventative vaccination among presumably cisgender sexual minority people, and this could have implications for vaccination information sharing through social media platforms that have growing use among TGD and sexual minority communities.<sup>34,35</sup> Research that explored information sharing using HINTS data found that use of social media for sharing health information declined over time, whereas use of social media to exchange medical information with a health professional increased.<sup>36</sup> These findings were based on a general population sample; the motivations for health information sharing among peers and/or healthcare professionals may be different for TGD people, especially those who have experienced discrimination and stigma in healthcare.<sup>37</sup>

A limited number of studies have investigated the association of online health information seeking and vaccination among presumably cisgender sexual minority people. A study of presumably cisgender men who have sex with men (MSM) showed an increase

**Table 4.** Odds of reporting HPV vaccination among TGD participants compared with cisgender sexual minority participants in The PRIDE Study in the United States (N = 3258)

	Preliminary Model P Value	Reduced Model aOR (95% CI)
Online health information seeking		
In the past 12 months, have you used a computer, smartphone, or other electronic means to look for health of medical information for yourself?	.1958	
In the past 12 months, have you used the Internet to look for information about vaccines for yourself?	.0193	0.7 (0.5-0.9)
Internet use		
In past 12 months, used a computer, smartphone, other electronic means to . . .		
Visit social networking site (eg, Facebook)	.0456	2.4 (1.1-5.6)
Track healthcare charges and costs	.0058	0.6 (0.5-0.9)
Make appointments with a healthcare provider	.0046	0.5 (0.4-0.9)
HPV knowledge		
Ever heard of HPV	.0091	2.1 (1.1-4.1)
Access to care		
Have Medicaid insurance	.0035	0.3 (0.1-0.7)
Preventative care		
Number of vaccines received since 18 years of age		
3 or more vaccines	.0015	3.5 (1.5-8.2)
1-2 vaccines	.1491	1.8 (0.7-4.4)
None	Ref.	
Had HIV test in past 12 mo	<.0001	2.0 (1.5-2.8)
Had anorectal cancer screening	.0006	0.6 (0.4-0.8)
Barriers to care		
Delayed medical care in past 12 mo	.0355	1.5 (1.1-2.0)
≤50% healthcare providers aware of your sexual orientation	.0304	0.7 (0.5-1.0)
≤50% healthcare providers aware of your gender identity	.0555	1.5 (1.0-2.1)
Demographics		
Gender identity TGD (ref. white)	.0607	1.5 (1.1-2.2)
Age ≤27 y	<.0001	0.08 (0.05-0.11)
Race/ethnicity	.0098	1.0 (0.9-1.1)
Education	.7283	1.0 (0.5-2.0)
$\chi^2$	274.1 <i>df</i> = 32, <i>P</i> < .0001	276.6, <i>df</i> = 17, <i>P</i> < .0001
Nagelkerke <i>R</i> <sup>2</sup>	34.3%	32.8%
Hosmer and Lemeshow test	<i>P</i> = .7162	<i>P</i> = .2835
Akaike information criterion score	1528.2	1546.8

aOR: adjusted odds ratio; CI: confidence interval; HPV: human papillomavirus; PCP: primary care provider; TGD: transgender and gender diverse.

in HPV vaccination among those who searched online for sexual health information.<sup>38</sup> Related research found that MSM had higher perceived benefits of HPV vaccination when they exhibited higher levels of health information orientation ( $\beta = 0.31$ ,  $B = 12.79$ ; 95% CI, 0.20-0.44); however, the sources of health information were not identified.<sup>39</sup> These findings are inconsistent with our primary finding that TGD participants were less likely to report HPV vaccination than cisgender sexual minority participants if they looked for vaccine information online. This difference could possibly be attributed to additional factors that increased perceived advantages of HPV vaccination among MSM, such as the presence of a perceived threat.<sup>39</sup> In addition, our study found that TGD participants reported increased HPV vaccination after using social media, which may have been an information source for vaccination. Our findings suggest that TGD people may be engaging with online health information differently than cisgender sexual minority people.

Having heard of HPV increased the likelihood of reporting HPV vaccination among TGD participants, which is consistent with the

literature that has examined knowledge of HPV and vaccination among sexual and gender minority communities.<sup>31,40,41</sup> Our findings that users who tracked healthcare costs and healthcare appointments using a computer, smartphone, or other electronic means was associated with decreased reporting of HPV vaccination warrants further investigation. Out-of-pocket costs for healthcare may be a perceived barrier to individuals who track costs closely. The cost of other vaccines is a barrier in presumably cisgender sexual minority people.<sup>42</sup> This would especially be true with lower income individuals who have Medicaid, which is consistent with our findings of decreased reporting of HPV vaccination among TGD participants with Medicaid. Decreased reporting of HPV vaccination among TGD participants who had made medical appointments online is possibly related to a perceived barrier to obtaining care if preventative care appointments are not readily available. In contrast, having had an HIV test in the past 12 months was associated with increased reporting of HPV vaccination, which corroborates studies that have shown an increase in preventative vaccination in presumably cisgender sexual minority people when HIV and STI testing were bundled



with vaccination.<sup>43–45</sup> The greatest effect sizes for reporting HPV vaccination were observed among TGD participants who had received 3-or-more vaccines (other than HPV) since 18 years of age. This is consistent with the literature that has demonstrated that when other vaccines such as hepatitis A/B are bundled together it can increase vaccine uptake among sexual and gender minority communities.<sup>46</sup>

Although we found no moderating effects of general health literacy or eHealth literacy, this is likely related to the highly health-literate sample who had generally high eHEALS scores and few challenges understanding health information. The lack of variability in general health literacy and eHealth literacy further limited any moderating effects.

### Strengths/limitations

This study has several strengths. To our knowledge, this is the first study to investigate the relationship between online health information seeking and HPV vaccination using a large sample of TGD people. From an informatics perspective, use of The PRIDE Study and its digital health research platform enabled our study team to leverage a novel national dataset that empowers TGD people to describe diverse gender identities and gender expressions. The Integrative Model of eHealth Use is a theoretical framework that has never been adapted to examine a specific health behavior outcome among TGD communities. In addition, we took a novel approach to operationalize the theoretical model and incorporate general health literacy and eHealth literacy as moderators.

The study is not, however, without its limitations. Although our cross-sectional survey was composed of items from previously validated instruments, our survey as a whole may not be considered a validated instrument because of the modifications made to items and mixture of items from multiple sources. The PRIDE Study is a convenience sample; since the majority of participants were white and had greater than a high school education, our sample was not representative of TGD and cisgender sexual minority people residing in the United States. TGD people were compared with cisgender sexual minority people in aggregate and comparison groups were categorized using sex assigned at birth and gender identity. However, comparison groups were not further stratified by specific gender identities and factors that are associated vaccine among different gender groups warrants further investigation. HPV vaccination by self-report may be subject to recall bias which may worsen over time. Lastly, the cross-sectional nature of the study limits our ability to derive any causal relationships.

### CONCLUSION

In summary, our study of online health information seeking and HPV vaccination found that compared with cisgender sexual minority people, TGD people reported increased HPV vaccination overall, but were less likely to report vaccination after they searched for vaccine information on the Internet. Factors most associated with HPV vaccination were having visited a social networking site like Facebook, having received 3-or-more vaccines since 18 years of age, and having heard of HPV. We found no moderating effects from general health literacy or eHealth literacy. Future studies should investigate potential deterrents to HPV vaccination in online health information to enhance its effectiveness, and further explore which aspects of social media might increase vaccine uptake among TGD and cisgender sexual minority people.

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### AUTHOR CONTRIBUTIONS

All authors have fulfilled the criteria for authorship established by the International Committee of Medical Journal Editors and approved submission of the manuscript. ATP, SB, and JO-M contributed substantially to the conception and design of the study. MRL made important intellectual contributions to the survey design and implementation. ATP conducted all the statistical analyses and drafted the manuscript. MEL and AF made important contributions to the study as experts in sexual and gender minority community engagement and sexual and gender minority mental health. ZD made important intellectual contributions to the study in the area of data use and management. All coauthors participated in the critical review of the manuscript, made important intellectual contributions, and approved the final version to be published.

### SUPPLEMENTARY MATERIAL

Supplementary material is available at *Journal of the American Medical Informatics Association* online

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### DATA AVAILABILITY STATEMENT

Members of the lesbian, gay, bisexual, transgender, and queer (LGBTQ+) communities have experienced significant stigma and discrimination from society including the medical and investigational communities. As such, we are ethically bound to upholding the principle of nonmaleficence; we promise our participants to not let any data (including deidentified) fall into the hands of people who may use it to publish stigmatizing results about the LGBTQ+ communities. For example, someone could look at the gender identities of racial/ethnic minorities and make claims that a specific racial/ethnic minority should be targeted to 'cure' people with a specific gender identity. As such, The PRIDE Study has developed an Ancillary Study process in which investigators interested in using PRIDE Study data submit an application which is reviewed by both a Research Advisory Committee (composed of scientists) and Participant Advisory Committee (composed of scientists and participants) to affirm appropriate data use and work in collaboration with The PRIDE Study for planning, analysis, and dissemination. Details about the Ancillary Study process are available at [www.pridestudy.org/collaborate](http://www.pridestudy.org/collaborate) or by contacting us at [support@pridestudy.org](mailto:support@pridestudy.org) or 855-421-9991 (toll-free).

## CONFLICT OF INTEREST STATEMENT

JO-M has served as a consultant for Sage Therapeutics (5/2017), Ibis Reproductive Health (a not-for-profit research group; 3/2017 to 5/2018, 2020 to present), Folx (2020 to present), and Hims (2019 to present). MRL has served as a consultant for Hims (2019 to present) and Folx (2020). AF has served as a consultant for Hopelab, a not-for-profit research group. None of these roles present a conflict of interest with this work as described here. All other authors have no conflicts of interest to report.

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