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Users of a National Directory of PrEP Service Providers: Beliefs, Self-Efficacy, and Progress toward Prescription

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To the editors

PrEP (HIV pre-exposure prophylaxis) is highly effective in preventing HIV transmission.^{1–3} In a meta-analysis by Fonner et al., PrEP was shown to reduce the risk of HIV acquisition by 70% for adherent users in all risk groups including men who have sex with men, heterosexually active adults and people who inject drugs.⁴ An estimated 98,732 individuals had initiated PrEP regimens from 2012–2016, whereas 1,232,000 adults in the United States were estimated to be indicated for PrEP in 2016 alone.^{5,6} More research is needed on how to facilitate PrEP uptake along the HIV prevention care continuum.

One previously identified barrier to care is locating a provider willing to prescribe PrEP.⁷ A tool recently developed by the authors, PrEP Locator, is an online national database of PrEP-providing clinics that provides information for the nearest clinics based on a user's location.⁸ The database of over 2100 clinics was originally developed from all available state health department directories, local health department directories, non-governmental organization directories, and HIV-related medical organization member surveys. It is routinely updated through a web form that allows clinics or the general public to suggest new clinics, with Emory staff vetting all clinics before inclusion in the database. Information provided to website visitors includes clinic contact information, a link-out for map-based directions to each clinic, and clinic search filters for individuals to identify services that assist with manufacturer copay programs or provide care for those without health insurance.

To explore user behavior before and after accessing PrEP Locator, from June–July 2017 we recruited users to complete baseline and one-month follow-up surveys. The recruitment ad showed immediately when users landed at PrEPLocator.org. Individuals using the website for personal use and over 18 years of age were eligible to take the survey. The survey collected data on demographics,⁹ PrEP eligibility,¹⁰ PrEP awareness,¹¹ PrEP knowledge,¹¹

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stage in the PrEP continuum,¹² positive beliefs about PrEP, negative beliefs about PrEP, and PrEP self-efficacy. After gathering awareness and knowledge of PrEP, both surveys offered a brief definition of PrEP and an explanation that insurance and other programs may help cover PrEP costs. To determine an individual's stage on the PrEP continuum, the study assessed whether individuals were: (1) not considering PrEP, (2) considering PrEP, (3) in the process of accessing PrEP, or (4) currently taking PrEP.¹² Individuals considered to be currently taking PrEP reported obtaining TDF/FTC for PrEP and not missing more than three doses per week, based on a 30-day recall question. Questions on positive beliefs, negative beliefs, and self-efficacy were developed by the authors. One month after completion of the baseline survey, participants were provided with a follow-up survey containing similar measures to the initial survey. Respondents were required to be HIV negative or of an unknown HIV status and complete the baseline and follow-up surveys to be included in this analysis. All research procedures were approved by Emory University's Institutional Review Board and followed the ethical standards of the Helsinki Declaration of 1975, as revised in 2000. To assess changes in the prevention continuum, a Wilcoxon signed rank sum test was used; for all other assessments McNemar's tests were used.

A total of 169 individuals clicked the recruitment ad and indicated whether they were using the locator for personal use (114/169), professional use (39/169), or other use (16/169). Among those selecting personal use, 54 were eligible, consented, and completed the baseline and follow-up surveys. The sample was predominantly male (53/54). Mean age was 43 years (standard deviation: 14.8). Participants were white (37/54), black (4/54), Hispanic (6/54), and other races (7/54). All identified as gay (44/54) or bisexual (10/54). About a fourth (13/54) reported not having health insurance. Using CDC criteria for PrEP eligibility,¹⁰ most (45/54) were indicated for PrEP based on self-reported sexual risk. None were indicated based on intravenous drug use risk. Most website users expected the website to be useful in the future (48/54). At follow up, 21 out of 54 participants reported that PrEP Locator helped them locate PrEP services, though not all of these individuals advanced through the PrEP continuum.

Table 1 shows PrEP continuum stage, PrEP awareness, PrEP knowledge, PrEP beliefs, and self-efficacy beliefs at baseline and one-month follow-up. At baseline, most were considering PrEP (45/54), one was not considering PrEP, one had a scheduled appointment to talk with a provider about starting PrEP, and seven were currently taking PrEP. At follow-up, fewer were considering PrEP (38/54), one was not considering PrEP, six had a scheduled appointment to talk with a provider about starting PrEP, and nine were currently taking PrEP. Reported adherence among those currently taking PrEP at baseline and follow-up was high, with none reporting missing more than 3 doses in the last 30 days. All individuals reported obtaining PrEP through formal channels, based on a prescription from their clinician. Changes in the PrEP continuum, towards care-seeking behaviors, were significant (Wilcoxon signed rank sum test p -value=0.02). PrEP awareness was high at baseline and follow-up. PrEP knowledge increased from baseline to follow-up, with six more individuals correctly indicating that PrEP is over 90% effective when taken every day (McNemar's test p -value=0.02).

Over four-fifths of participants endorsed positive PrEP belief statements at baseline, with the exception of a statement regarding PrEP few side effects (38/54). Less than half of participants endorsed negative PrEP belief statements at baseline, with the exception of a statement regarding PrEP cost concerns (34/54). Over four-fifths of participants endorsed PrEP self-efficacy statements at baseline, with the exception of a statement regarding perceived ability to obtain a PrEP prescription (36/54). No changes in positive beliefs, negative beliefs, or self-efficacy were observed between baseline and follow-up, except a decline in agreement with perceived ability to obtain a PrEP prescription (McNemar's test p -value=0.02).

This exploratory study of PrEP Locator website users indicates that most users completing a survey considered the website to be a useful tool, over one-third at follow-up noted that it helped them find a PrEP provider, and a minority positively progressed in the PrEP care continuum. Study participants were likely landing on the Locator webpage due to interest in or curiosity about PrEP, so our findings do not suggest causation between website use and PrEP-seeking behavior. Instead, our findings indicate that the website could be serving its intended purpose, with a proportion of users subsequently accessing PrEP. This suggests that simple interventions to reduce barriers to accessing appropriate care have the potential to be impactful, although further research that includes a control condition would be required to demonstrate causation. Anecdotally, both clinicians and community-based colleagues have described to the study authors the benefit of having the website to facilitate easy referral for persons interested in accessing PrEP. The utility of PrEP Locator is likely the reason that, in absence of an advertising budget, the website has experienced over 150,000 unique users and over 290,000 page views in the 18 months since launch.

Overall, participants were likely to endorse positive statements about PrEP, unlikely to endorse negative statements, and likely to endorse PrEP self-efficacy statements. The primary exceptions were negative beliefs about PrEP costs and about self-efficacy to obtain a PrEP prescription. These issues have both been previously identified as barriers to care.^{13,14} Not only were these issues identified at baseline, but they remained at the one-month follow-up. In fact, compared to baseline, more PrEP Locator users at follow-up anticipated they would not be able to get a PrEP prescription. It is possible that these changes in perception arose from an increased familiarity with PrEP, despite the availability of navigation programs that seek to minimize the cost of seeking PrEP.

This study is limited in that it is based on a small, convenience sample of users of a PrEP-seeking website, and there is no control condition to allow for comparison. These limitations prevent us from drawing any causal conclusions. Without a representative sample or a control group, and given known selection bias, it is possible that observed progress through the PrEP continuum is unrelated to PrEP Locator. Therefore, this study can only establish the possibility that the website may contribute to movement along the continuum. Conclusions drawn from data regarding the reported usefulness of the Locator, identification of cost as a problem, and reported low self-efficacy to obtain PrEP only seek to describe website users, and are not influenced by the lack of comparison to a control condition. Additionally, the convenience sample may have also affected the endorsement of negative, positive and self-efficacy beliefs, as a sample that is using a PrEP location service,

presumably either due to interest in PrEP or an intention to initiate PrEP, is likely to have more favorable views of PrEP than the general population. Though it is possible that informal use of PrEP could influence one's PrEP perceptions, all our respondents on PrEP reported obtaining it through official sources, and therefore we do not suspect this to have occurred.

The study shows that a simple, geolocated service directory has the potential to help patients seek care. Cost and difficulty of obtaining a prescription are common barriers in the PrEP continuum. Other low-cost interventions that remove barriers to seeking and remaining in PrEP care are needed. Additionally, visitors to this and other service directory websites may benefit from enhanced service navigation.

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Differences in Stage in PrEP Continuum, Awareness, Knowledge, and Beliefs in Four Week Period Following the Use of an Online PrEP Location Service

Table 1

	Baseline		Follow-Up	
	%	n/N	%	n/N
Stage in PrEP Continuum *				
<i>Would not consider taking PrEP</i>	1.9	1/54	1.9	1/54
<i>Would consider taking PrEP</i>	83.3	45/54	70.4	38/54
<i>Has an appointment to talk to a clinician about starting a PrEP regimen</i>	1.9	1/54	11.1	6/54
<i>Has a PrEP prescription and is currently taking PrEP</i>	12.9	7/54	16.7	9/54
Awareness				
Before today, have you ever heard of people who do not have HIV taking PrEP (HIV prevention with antiretroviral pills)?				
Yes	94.4	51/54	96.3	52/54
I'm not sure	3.7	2/54	3.7	2/54
No	1.9	1/54	0	0
Knowledge¹				
How effective is PrEP at preventing HIV infection if a person takes their pills every day? *				
More than 90% effective	81.5	44/53	94.4	51/54
Less than 90% effective	17.0	9/53	5.6	3/54
Positive Beliefs, agree or strongly agree with the statement				
<i>PrEP is valuable because it prevents HIV transmission.</i>	98.1	53/54	100	54/54
<i>PrEP is valuable because it provides peace of mind.</i>	92.6	50/54	94.4	51/54
<i>PrEP is valuable because I can help take care of my community.</i>	85.2	46/54	87.0	47/54
<i>PrEP is valuable because it is the most effective way to prevent HIV transmission.</i>	83.3	45/54	77.8	42/54
<i>PrEP is valuable because, as a daily pill, it is easy to take.</i>	88.9	48/54	88.9	48/54
<i>PrEP is valuable because it has few major side effects.</i>	70.4	38/54	70.4	38/54
Negative Beliefs, agree or strongly agree with the statement				
<i>Taking PrEP daily is a problem.</i>	13.0	7/54	24.1	13/54
<i>Taking medicine even though I am healthy is a problem.</i>	16.7	9/54	16.7	9/54
<i>The failure of PrEP to prevent sexually transmitted infections (STIs) is a problem.</i>	35.2	19/54	31.5	17/54

	Baseline		Follow-Up	
	%	n/N	%	n/N
<i>The side effects of PrEP are a problem.</i>	20.3	11/54	22.2	12/54
<i>The cost of PrEP is a problem.</i>	63.0	34/54	72.2	39/54
<i>The possibility of drug resistance if I contract HIV while on PrEP is a problem.</i>	44.4	24/54	44.4	24/54
Self-Efficacy , agree or strongly agree with the statement				
<i>I am motivated to take PrEP.</i>	90.7	49/54	87.0	47/54
<i>If I wanted to be on PrEP, I would be able to get a prescription.*</i>	66.7	36/54	46.3	25/54
<i>If I wanted to be on PrEP, I would be able to take it each and every day.</i>	94.4	51/54	92.6	50/54
<i>If I wanted to be on PrEP, I would be able to take it when I feel depressed, bored or stressed.</i>	81.5	44/54	85.2	46/54
<i>If I wanted to be on PrEP, I would be able to take it when I am very busy.</i>	92.6	50/54	88.9	48/54

* denotes $p < 0.05$ significance for change in baseline to follow-up

J The presented binary outcome was derived from a multiple-choice question with the choices: More than 90% effective, 75–89% effective, 50–74% effective, 35–49% effective, 20–34% effective, or less than 20% effective.