BMC Health Services Research

RESEARCH

Open Access

An electronic health record-based strategy to increase PrEP decision-making among cisgender women in primary care: results of a randomized pilot study

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Abstract

Background Approximately one in five HIV infections in the United States occurs among cisgender women, those whose gender identity matches their sex assigned at birth. Pre-exposure prophylaxis (PrEP) is a highly effective preventive option for all genders, yet lack of awareness and stigma have hindered uptake. To address this gap, we sought to develop and pilot test an electronic health record-based strategy among cisgender women in primary care.

Methods Our strategy, informed by prior work, identified cisgender women in primary care who might benefit from PrEP, provided them with person-centered PrEP educational materials via the patient portal, and offered an opportunity to electronically request a dedicated PrEP visit with a PrEP champion – a female primary care physician – if desired. We conducted two sequential patient-randomized pilot studies to test: (1) the efficacy of the materials compared to usual care, and (2) the preliminary effectiveness of our strategy compared to usual care. The primary outcomes for the efficacy study included PrEP knowledge and PrEP stigma, while the primary outcome for the preliminary effectiveness study was PrEP uptake over a three-month period.

Results In total, we enrolled 200 women. The efficacy study ($n=100$, $n=50$ per arm) revealed our PrEP educational materials significantly increased PrEP knowledge scores among women who were directly shown the materials, compared to those who were not (9.4 (standard deviation (SD) 0.9) vs. 5.8 (SD 1.8) out of 10, p-value <0.01, respectively). However, the preliminary effectiveness study ($n=100$, $n=50$ per arm) resulted in no significant differences, other than PrEP awareness, between women randomized to our strategy and those randomized to usual care.

Conclusions PrEP educational materials have the potential to increase PrEP knowledge among cisgender women. For the patient portal to be an effective delivery channel, additional support efforts should be considered.

Trial registration The study was registered at ClinicalTrials.Gov, Clinical Trial number NCT05709860 registered on 2023-01-17.

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Keywords PrEP, Cisgender women, Primary care, Patient portal intervention, Patient education

Introduction

In the United States, HIV among cisgender women, those whose gender identity matches their sex assigned at birth, is a significant yet often overlooked public health concern [1]. Although nearly one in five HIV infections occurs among cisgender women (herein referred to as women), preventative services are largely targeted towards men who have sex with men [2, 3].

Pre-exposure prophylaxis (PrEP) is an antiretroviral medication that is highly effective at preventing HIV when used as prescribed [4]. Unlike condoms, PrEP can be initiated and used without partner involvement. It is currently available to women as a daily pill or bi-monthly injection, though additional options may soon available [5]. Despite its effectiveness, national data indicate women represent only 8% of PrEP users [6].

Prior studies have shown that lack of awareness and stigma are key barriers to PrEP use among women [7–9]. Furthermore, although women have noted a preference for primary care providers to normalize PrEP conversations during clinic visits, providers have reported they are not always adequately prepared to counsel on or prescribe PrEP to women [1].

Chicago, Illinois is one of the locations with the highest HIV prevalences in the United States [6], and was the location for this study. However, within the participating health system, no standardized approach is currently followed to initiate PrEP counseling or prescribing with women.

To address these gaps, we built upon prior successful work by our team that utilized health information and consumer technologies to prompt safe prescribing, counseling, and use of specialized medications [10, 11]. The result was our novel PrEP Champion Strategy. It sought to: (1) identify women in primary care who might benefit from PrEP; (2) provide them with person-centered PrEP educational materials via the patient portal; and (3) offer them an opportunity to electronically request a dedicated PrEP visit with a PrEP Champion – a female primary care physician experienced in PrEP delivery. This paper describes the development of our strategy and results of two sequential, patient-randomized pilot studies, examining the efficacy of our materials and the preliminary effectiveness of our PrEP Champion Strategy.

Methods

Identification of eligible patients

At the time of strategy development, the Centers for Disease Control and Prevention (CDC) guidelines listed specific indications for PrEP [12]. This guidance, coupled with health system constraints, resulted in a need to identify a target population for whom our strategy would be appropriate. To achieve this, we worked with the electronic data warehouse (EDW) team to identify primary care practices, within the participating health center, that reported conducting the greatest number of tests (≥ 50 in the past year) for chlamydia, gonorrhea, and/or syphilis among women. Tests for these sexually transmitted bacterial infections were of specific interest as these infections are known to increase vulnerability to HIV [13, 14]. From this list, we subsequently selected practices that were also located in the downtown Chicago, Illinois area.

We then created an electronic health record (EHR) query to identify a target population of women within those practices who could potentially benefit from PrEP and, thus, receive our educational materials. The target population needed to have EHR data indicating they: (1) were English-speaking; (2) aged 18 years or older; (3) HIV negative; (4) identified as a cisgender woman; and (5) were seen in the prior week at one of the previously mentioned primary care practices, as this was thought to facilitate a slow roll out of our strategy. Additionally, the target population needed to have: 6a) tested multiple times in the past year for chlamydia, gonorrhea, and/or syphilis; or 6b) received a positive diagnosis for one or more those sexually transmitted bacterial infections in the past six months. Women were excluded from the target population if they were pregnant or had ever used, or were currently using, PrEP.

Development of our educational materials and encompassing PrEP champion strategy

Our person-centered PrEP educational materials were developed through a review of the literature and available PrEP awareness campaigns; they consisted of a three-page print material and a two-minute video (akin to a social media reel). Both materials were designed using health literacy best practices and with the help of a professional graphic designer [15]. An initial draft of the materials was reviewed and enhanced by an external scientific advisory board comprised of two researchers and one physician with expertise in HIV prevention. The materials were then optimized via cognitive interviews with a diverse group of women (N = 15) identified from the participating health center and social media platforms [16].

Once optimized, the goal was to send the educational materials to the target population via the patient portal; as a form of quality improvement, this did not require informed consent. Specifically, eligible women received an email prompting them to securely log into their patient portal accounts to view a brief message and

health educational materials that could be of interest to them. The secure portal message they received provided instructions for women to click on the three-page print material and/or view the two-minute video (see Supplementary Materials).

The message also provided instructions on how to discretely request a telehealth or in-person visit with a PrEP Champion – if desired. Champions for this study were two female primary care physicians with expertise in PrEP counseling and delivery to diverse individuals; they were located at the same downtown primary care practice and expressed an interest in supporting the study by reserving time in their schedules for dedicated PrEP visits, if requested by the target population. The PrEP educational materials and the portal message both informed recipients that our PrEP Champions were available to provide them with additional information and/or PrEP prescriptions if desired and appropriate. To capitalize on potential interests, and to reduce barriers imposed by long wait periods, visits were available for 'immediate' scheduling; within the context of the participating health system, that equated to a visit within a two-week period. Regular billing procedures were intended to be followed.

Evaluation

Study design and clinical trial registration We obtained approval to develop, implement, and evaluate our PrEP Champion Strategy by the Northwestern University Institutional Review Board (STU#: STU00217596) and from multiple health system advisory committees (communications, informatics, etc.). We then conducted two sequential, two-armed, patient-randomized pilot studies using post-test designs among participants from the participating academic health system. One study facilitated an examination of the efficacy of our materials (whether, compared to usual care, our materials were associated with increased PrEP knowledge and reduced PrEP stigma), while the other assessed the preliminary effectiveness of our PrEP Champion Strategy (whether, compared to usual care, our strategy was associated with increased PrEP uptake during a three-month follow-up). Together, these studies were registered at ClinicalTrials.Gov: NCT05709860. Randomization, eligibility, recruitment, and consent procedures were identical for the two studies, while the manner in which participants were exposed to our materials differed slightly, as did the outcomes of interest. We detail this below.

Randomization We added a randomization feature to the EHR query such that, each week, the target population was randomized to one of two study arms: the PrEP Champion Strategy arm or the usual care arm (see the CONSORT flow diagram). This process was the same for our sequential studies (efficacy and preliminary effectiveness). Those in the strategy arm were sent, via the patient portal, our PrEP educational materials and offered an opportunity to electronically request a dedicated PrEP visit, while those in the usual care arm were not.

Participant eligibility, recruitment, and consent To evaluate our materials and our encompassing strategy, we conducted individual, remote, post-test interviews. Eligibility criteria for study interviews mirrored that of the target population described above; however, for remote interviewing purposes, study participants also needed to have access to a phone and/or the ability to use a secure videoconferencing platform. After individuals were randomized to either the strategy or usual care arm, trained research coordinators (RCs) phoned them for study recruitment. During recruitment calls, RCs confirmed eligibility and interest. Those eligible and interested were engaged in an electronic informed consent process; interviews were then scheduled with consented participants.

Data collection Between November 2023 and July 2024, RCs conducted structured interviews with consented participants over the phone or a secure videoconferencing platform; all responses were recorded in REDCap software [17]. Interviews lasted approximately 30 min and participants were compensated $45.

Efficacy study procedures For the efficacy study, RCs began interviews with consented participants randomized to our strategy by showing our PrEP educational materials over secure videoconferencing technology – even though those participants had also received the materials in their patient portals along with instructions to electronically request a dedicated PrEP visit if desired. This process was conducted to ensure strategy arm participants viewed the materials prior to answering interview questions; it is a process we have used in other studies testing the efficacy of health education materials [18–20].

Efficacy study measures Interviews with participants included measures of sociodemographic characteristics, including age, race and ethnicity, education, and income levels. Patient activation, or an individual's willingness to actively manage their health, was measured by the validated Consumer Health Activation Index (CHAI); participants were classified as having low, moderate, or high activation [21]. Health literacy was measured using the validated three-item screener; this measure classified participants as having limited or adequate health literacy [22]. Perceived risk of HIV was measured using a validated scale with higher summed scores representing greater perceived risk [23].

For the efficacy study, we were primarily interested in examining whether our materials were associated with

increased PrEP knowledge and reduced PrEP stigma. PrEP knowledge was assessed using a 10-item index developed by the study team and adapted from scientific literature [24]; scores were summed with higher scores representing greater PrEP knowledge. PrEP stigma was measured using a five-item scale, with higher scores representing greater PrEP stigma [24]. Secondarily, we were interested in how participants perceived our materials. Single item questions asked participants randomized to our strategy to rate their level of satisfaction with the appearance and quality (separately) of the materials on a 10-point Likert scale, as we have in prior studies [18, 19]. Finally, we also examined PrEP awareness in this condition, largely to identify if there were any differences by study arm. This was measured using a single item asking participants to respond (yes/no) to the following question: "Before today (this interview), had you ever heard of pre-exposure prophylaxis or PrEP?"

Preliminary effectiveness study procedures For the preliminary effectiveness study, participants randomized to our strategy were sent the materials and instructions to electronically request a dedicated PrEP visit, if desired, just like for the efficacy study. The difference, however, was that RCs did not show participants the materials ahead of the study interview. This process was conducted to mimic real-world settings and, therefore, assess the preliminary effectiveness of our strategy compared to usual care.

Preliminary effectiveness study measures The same measures of sociodemographic characteristics, patient activation, health literacy, and perceived risk of HIV that were assessed in the efficacy study were also assessed among all participants in the preliminary effectiveness study.

Yet, for the preliminary effectiveness study, the primary outcome of interest was PrEP uptake; this was measured using data in the EHR detailing whether PrEP prescriptions were issued within three months after enrollment and was compared between study arms. Secondary outcomes included PrEP awareness, knowledge, stigma, and process measures. PrEP awareness was measured using the same single item from the efficacy condition, though participants were also asked to identify sources of PrEP information to examine whether they had learned of PrEP through the portal. PrEP knowledge and PrEP stigma were assessed using the same measures described above in the efficacy study. Process measures were captured to further elucidate preliminary effectiveness; these measures were assessed in the EHR and revealed whether participants randomized to our strategy opened the PrEP educational print materials, viewed the video, and whether they scheduled a PrEP visit.

Analysis

Analyses for both studies included descriptive statistics for sociodemographic variables, health literacy, and patient activation levels, while descriptive statistics were also conducted for process outcomes and perceived satisfaction. Bivariate analyses identified any significant differences in PrEP uptake, knowledge, and stigma by study arm. Fisher's exact tests were performed for all variables where cell sizes were less than 10. Cronbach's alphas were calculated to assess the internal consistency of scales. P-values less than 0.05 were considered statistically significant. All analyses were preformed using SAS 9.4.

Results

Results are presented and discussed below by study.

Efficacy study participant characteristics

The efficacy study enrolled a total of 100 participants (n = 50 usual care, n = 50 strategy). Participant characteristics are shown in Table 1. On average, these participants were 36 years of age. Most self-reported they were non-Hispanic (82%), non-white (57%), and college graduates (81%). A total of 40% were married or living with a partner (data not shown) and over half (57%) reported having an annual income of $75,000 or greater. A total of 25% were classified as having low heath literacy, and 65% as having low patient activation. The average perceived risk of HIV was 18.9 (scale 10 to 40). No characteristics were significantly different between arms.

Efficacy study outcomes

Outcomes from the efficacy study are presented in Table 2. Participants in the strategy arm were statistically more likely to have greater PrEP knowledge than those in usual care (p-value < 0.01). The mean knowledge score was 9.4 out of 10 in the strategy arm, compared to 5.8 in usual care. No other significant differences were noted between arms.

Material satisfaction data, collected only among participants in the strategy arm, is presented in Table 3. In general, participants were satisfied with our PrEP materials, providing an average score of 7.8 (scale of 1 to 10) for material appearance and 8.5 (scale of 1 to 10) for material quality.

Preliminary effectiveness study participant characteristics

Similar to the efficacy study, the preliminary effectiveness study enrolled a total of 100 participants (n = 50 usual care, n = 50 strategy). Characteristics of participants in the preliminary effectiveness study are presented in Table 4. In brief, these participants had an average age of 37 years. Most self-reported they were non-Hispanic (87%), non-white (54%), and college graduates (81%). A total of 36% were married or living with a partner (data

Table 1 Characteristics of efficacy study participants

	Overall (*n* = 100)	Usual Care (*n* = 50)	Strategy (*n* = 50)	*P*-value
Age				0. 64
Mean (SD)	35.9 (10.2)	35.4 (8.4)	36.3 (11.7)	
Median (Range)	34 (21–78)	36 (21–60)	34 (21–78)	
Ethnicity, n (%)				0.30
Hispanic	18 (18.0)	7 (14.0)	11 (22.0)	
Not Hispanic	82 (82.0)	43 (86.0)	39 (78.0)	
Race, n (%)				0.49
White/Caucasian	43 (43.0)	21 (42.0)	22 (44.0)	
Black/African American	31 (31.0)	18 (36.0)	13 (26.0)	
Other*	26 (26.0)	11 (22.0)	15 (308)	
Education, n (%)				0.09
High School Graduate	5 (5.0)	5 (10.0)	-	
Some College	14 (14.0)	7 (14.0)	7 (14.0)	
College Graduate	81 (81.0)	38 (76.0)	43 (86.0)	
Income, n (%)				0.42
< $50,000	21 (21.0)	13 (26.0)	8 (16.0)	
$50,000-$74,999	22 (22.0)	9 (18.0)	13 (26.0)	
$75,000 or more	57 (57.0)	28 (56.0)	29 (58.0)	
Health Literacy, n (%)				0.82
Limited	25 (25.0)	13 (26.0)	12 (24.0)	
Adequate	75 (75.0)	37 (74.0)	38 (76.0)	
Patient Activation Level (CHAI), n (%)				0.06
Low	65 (65.0)	36 (72.0)	29 (58.0)	
Moderate	28 (28.0)	9 (18.0)	19 (38.0)	
High	7 (7.0)	5 (10.0)	2 (4.0)	
Perceived risk of HIV				0.87
Mean (SD)	18.9 (4.9)	19.0 (5.4)	18.9 (4.3)	
Median (Range)	19 (10–30)	19.0 (10.0–30.0)	19.0 (11.0–29.0)	

*Other race was broad, including Asian, Arabian, Hispanic, Multiple, Native American, Puerto Rican, and Don't Know or Refused

Table 2 Efficacy study outcomes by arm

	Usual Care (*n* = 50)	Strategy (*n* = 50)	*P*-value
Ever heard of PrEP, n (%)	28 (56.0)	32 (64.0)	0.41
PrEP Knowledge			*< 0.01*
Mean (SD)	5.8 (1.8)	9.4 (0.9)	
Median (Range)	6.0 (2.0–10.0)	10.0 (6.0–10.0)	
PrEP Stigma			0.14
Mean (SD)	11.6 (4.5)	10.3 (3.9)	
Median (Range)	10.5 (5.0–24.0)	10.0 (5.0–20.0)	

Italic text indicates *p*-values less than 0.05. Cronbach's alphas were 0.69 for PrEP knowledge and 0.79 for PrEP stigma

Table 3 PrEP material satisfaction

	Strategy (*n* = 50)
Appearance of the print material	
Mean (SD)	7.8 (1.6)
Median (Range)	8.0 (5.0–10.0)
Quality of the print material	
Mean (SD)	8.5 (1.8)
Median (Range)	9.0 (5.0–10.0)

not shown) and many (61.6%) had an annual income of $75,000 or greater. A total of (17%) were classified as having low health literacy and 60% as having low patient activation. The average perceived risk of HIV was 19.4 (scale 10 to 40). Race was the only characteristic that was significantly different between arms.

Preliminary effectiveness outcomes and process findings

Outcomes for the preliminary effectiveness study are presented in Table 5. Participants in the strategy arm were statistically more likely to have ever heard of PrEP than those in the usual care arm (p-value = 0.02). Moreover, in the strategy arm, 22% of participants reported hearing about PrEP from a healthcare provider or the patient portal, compared to 4% in the usual care arm, (*p*-value < 0.01). No participants scheduled a PrEP visit, and therefore, none met with a PrEP Champion or were prescribed PrEP. No other significant differences were noted between arms. In the strategy arm, 64% opened the email with print materials and 8% viewed the video.

Table 4 Characteristics of preliminary effectiveness study participants

	Overall (*n* = 100)	**Usual Care (*n* = 50)**	**Strategy (*n* = 50)**	***P*-value**
Age				0.80
Mean (SD)	36.5 (10.4)	36.7 (10.2)	36.2 (10.7)	
Median (Range)	35 (22–72)	35 (22–72)	35 (22–71)	
Ethnicity, n (%)				0.07
Hispanic	13 (13.0)	10 (20.0)	3 (6.0)	
Not Hispanic	87 (87.0)	40 (80.0)	47 (94.0)	
Race, n (%)				*0.04*
White/Caucasian	46 (46.0)	23 (46.0)	23 (46.0)	
Black/African American	35 (35.0)	13 (26.0)	22 (44.0)	
Other*	19 (19.0)	14 (28.0)	5 (10.0)	
Education, n (%)				1.0
High School Graduate	4 (4.0)	2 (4.0)	2 (4.0)	
Some College	15 (15.0)	7 (14.0)	8 (16.0)	
College Graduate	81 (81.0)	41 (82.0)	40 (80.0)	
Income, n (%)				0.78
< $50,000	19 (19.2)	10 (10.0)	9 (18.4)	
$50,000-$74,999	19 (19.2)	11 (22.0)	8 (16.3)	
$75,000 or more	61 (61.6)	29 (58.0)	32 (65.3)	
Health Literacy, n (%)				0.79
Limited	17 (17.0)	9 (18.0)	8 (16.0)	
Adequate	83 (83.0)	41 (82.0)	42 (84.0)	
Patient Activation, n (%)				0.09
Low	60 (60.0)	25 (50.0)	35 (70.0)	
Moderate	32 (32.0)	21 (42.0)	11 (22.0)	
High	8 (8.0)	4 (8.0)	4 (8.0)	
Perceived risk of HIV				0.94
Mean (SD)	19.4 (5.0)	19.3 (5.0)	19.4 (5.0)	
Median (Range)	19 (11–35)	19 (11–35)	20 (11–28)	

Italic text indicates *p*-values less than 0.05. *Other race was broad, including African, Asian, Hispanic, Middle Eastern, Multiple, Native American, Puerto Rican, and Don't Know or Refused

Table 5 Preliminary effectiveness study outcomes and process findings

	Usual Care (*n* = 50)	**Strategy (*n* = 50)**	***P*-value**
Ever Heard of PrEP, n (%)	28 (56.0)	39 (78.0)	*0.02*
Source, n (%)			
Friends	6 (12.0)	13 (26.0)	0.07
Healthcare providers/Patient portal	2 (4.0)	11 (22.0)	*< 0.01*
Website (other than social media)/The news	5 (10.0)	12 (24.0)	0.06
Other	26 (52.0)	35 (70.0)	0.10
PrEP Knowledge			0.49
Mean (SD)	5.5 (2.5)	5.9 (2.2)	
Median (Range)	6 (0–9)	6 (2–10)	
PrEP Stigma			0.90
Mean (SD)	10.9 (4.2)	10.8 (4.0)	
Median (Range)	11 (5–18)	11 (5–21)	
PrEP Uptake	0 (0.0)	0 (0.0)	
Scheduled a PrEP Visit n (%)	--	0 (0.0)	
Opened Print Materials n (%)	--	34 (64.0)	
Viewed Video n (%)	--	4 (8.0)	

Italic text indicates *p*-values less than 0.05. Cronbach's alphas were 0.68 for PrEP knowledge and 0.79 for PrEP stigma

Discussion

This paper presented the development and evaluation of our PrEP Champion Strategy. During our development activities, we utilized a collaborative process, informed by health literacy best practices [15], to create person-centered PrEP educational materials for cisgender women. Our strategy was designed to send print and video materials securely, via the patient portal, to women in primary care. The materials also offered recipients an opportunity to discreetly request a remote or in-person visit with a PrEP Champion – a female, primary care physician experienced in PrEP delivery. This would allow recipients to consider a PrEP prescription, if desired and appropriate. The process is novel and has the potential to positively disrupt health systems by using champions to deliver specialty care in primary care settings. Other studies have shown that co-locating specialty care in primary care settings supports high value care delivery [25]; however, although PrEP delivery in primary care is possible, training physicians has historically been challenging [26, 27], with one study showing primary care physicians report mixed opinions on whether they prefer having all physicians trained on PrEP delivery or having a PrEP champion [28]. To our knowledge, our study is the first in the United States to implement a strategy using select physicians as champions for PrEP delivery in primary care.

The consecutive studies presented in this paper sought to assess: (1) the efficacy of our materials and (2) the preliminary effectiveness of our PrEP Champion Strategy. During the efficacy study, participants randomized to our strategy were directly shown our PrEP educational materials, and post-test analyses revealed they had higher PrEP knowledge than those in the usual care arm. Moreover, participants were largely satisfied with the appearance and quality of the materials. Other studies have similarly shown that health education materials developed with end-user input are efficacious, providing readable and understandable information that is not only appealing, but also results in increased health knowledge [18, 20].

However, the preliminary effectiveness study revealed that relying on participants to view materials on their own, in the patient portal, is not a sufficient strategy. The only outcome that was statistically significantly different between arms in the preliminary effectiveness study was PrEP awareness, with participants in the strategy arm more likely to report having heard of PrEP than those in usual care. This was largely attributed to awareness from a healthcare provider or the patient portal, suggesting that while 64% of participants opened our PrEP materials in their patient portal accounts, they did not meaningfully engage with or learn from them. Although the patient portal has been identified as a potentially useful channel for delivering health education, including education about HIV and other sexually transmitted infections [29], our results suggest that additional support may be necessary to ensure individuals meaningfully engage with the materials sent to them. Researchers should also seek to ensure equitable access to the patient portal and identify support efforts patients perceive to be both acceptable and effective [30].

The preliminary effectiveness study also revealed no participants, regardless of study arm, were prescribed PrEP within three months of enrollment. Process measures further indicated that few participants, if any, engaged with our strategy components, including viewing the video or requesting a dedicated PrEP visit. This discrete scheduling feature sought to capitalize on participants' receipt of PrEP information and to circumvent the need to voice one's interest in PrEP to a clinic scheduler or to one's own primary care clinician during a visit focused on other health needs. Online self-scheduling has been promoted by consumer technologies, health systems, and patients alike as a convenient, acceptable, and potentially effective tool for increasing patient engagement in health services [31–33]. Empirical research has also shown online self-scheduling increases the uptake of more commonly utilized health services such as COVID-19 testing and influenza vaccinations [34, 35]. Yet, PrEP uptake is deeply rooted in personal choice, perceived risk of HIV, and stigma related to both HIV and to PrEP [2, 36, 37]. It may be that different delivery timings or subsets of women should be considered; for example, women with recently confirmed bacterial sexually transmitted infections may respond differently to PrEP materials than others.

Finally, although we had hoped our PrEP educational materials and our PrEP Champion Strategy might reduce individual-level PrEP stigma by providing a positive view of PrEP, we did not see this in either study. Four decades into the HIV pandemic, stigma remains a formidable barrier to prevention [8, 38, 39]; both HIV stigma and PrEP stigma could have contributed to the lack of engagement participants had in our study. As prior work suggests, a systems approach, as opposed to a more individual-level approach, may be needed to change HIV-related stigma within healthcare settings [40].

Together, these two pilot studies are not without limitations. All participants were recruited from a single academic health center, were generally well educated and had adequate health literacy. Despite this, they still were not meaningfully engaging in the PrEP educational materials sent to them via the patient portal. Furthermore, our sample sizes were relatively small, intended to show initial effects. It may be that with a larger sample size, comprised of more activated participants with higher

perceived risk of HIV, we would have seen different results.

Conclusions

In conclusion, our person-centered PrEP educational materials have the potential to increase PrEP knowledge; however, delivery of these materials via the patient portal does not guarantee meaningful engagement with them.

Abbreviations

PrEP Pre-exposure prophylaxis
CDC Centers for Disease Control and Prevention
EDW Electronic data warehouse
EHR Electronic health record
RCs Research coordinators
CHAI Consumer health activation index

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12913-025-12745-2.

Supplementary Material 1.

Acknowledgements

None.

Prior presentations

Not applicable.

Authors' contributions

APP: Conceptualization; funding acquisition; methodology; supervision; writing – original draft. RC: Conceptualization; methodology; writing – review and editing. RV: Conceptualization; resources; writing – review and editing. DV: Conceptualization; resources; writing – review and editing. MCM: Conceptualization; resources; writing – review and editing. KA: Investigation; formal analysis; writing – review and editing. RS: Investigation; formal analysis; writing – review and editing. GW: Formal analysis; project administration; writing – review and editing. RT: Conceptualization; resources; writing – review and editing. FY: Formal analysis; writing – review and editing. LMC: Conceptualization; supervision; formal analysis; writing – review and editing. SH: Formal analysis; resources; writing – review and editing. SCB: Conceptualization; supervision; writing – review and editing.

Funding

This work was supported by funding from Merck, Sharp & Dohme, LLC (MISP Reference #100089). The work was also funded in part, by the National Institutes of Health's National Institute on Aging, Grant Number P30 AG059988. REDCap software is supported by the National Institutes of Health's National Center for Advancing Translational Sciences, Grant Number UL1 TR001422. The opinions expressed in this paper are those of the authors and do not necessarily represent National Institutes of Health.

Data availability

De-identified data supporting the findings presented in this article may be available from the corresponding author; a reasonable request must be made from a qualified researcher and approval must be obtained from Northwestern University.

Declarations

Ethics approval and consent to participate

Ethical approval was obtained from the Northwestern University Institutional Review Board (STU00217596).
Participants were not required to provide consent for the receipt of PrEP educational materials. However, all participants who were included in pilot study interviews provided informed electronic written consent to patriciate.
All research activities were conducted in accordance with relevant guidelines and regulations, including the Declaration of Helsinki

Consent for publication

Not applicable.

Competing interests

The authors declare the following financial/personal relationships which may be considered as potential competing interests: Dr. Pack reports grants from Merck, Pfizer, Lundbeck, Gilead, and Eli Lilly through her institution; and personal consulting fees from Gilead. Dr. Bailey reports grants from the NIH, Merck, Pfizer, Lundbeck, Gilead and Eli Lilly through her institution; and personal consulting fees from Gilead, Pfizer, University of Westminster, Lundbeck, and Luto outside the submitted work. Dr. Masters reports grants from the NIH and Merck through her institution.

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Received: 4 December 2024 / Accepted: 12 April 2025
Published online: 24 April 2025

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