

# HIV pre-exposure prophylaxis (PrEP) for women: Claiming risk and recognizing responsibility to end the AIDS epidemic in New York

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## Abstract

**Introduction:** When the drug Truvada was approved for use as pre-exposure prophylaxis (PrEP) to prevent HIV in 2012, it was lauded as the first major advance in HIV prevention in decades and a major step toward reaching the goal of ending the epidemic. However, concerns around equitable access to PrEP arose quickly. This paper analyzes the ways in which one large-scale public health campaign framed its messaging around PrEP differently for women than for men, and suggests a more inclusive re-thinking of how 'risk' for HIV is conceived.

**Methods:** This analysis is based on 14 months (October 2014 – December 2015) of ethnographic research conducted in the context of New York State's 'Ending the Epidemic' (ETE) campaign. Participant observation was conducted at public meetings and events related to ETE and 37 semi-structured qualitative interviews were conducted with direct participants in the campaign, as well as with members of affected communities. Analysis also included review of documents related to ETE, such as reports, newspaper articles, and blog posts.

**Results:** Some prominent women involved in ETE felt that the campaign was largely run by men in its early days. While campaign messaging around PrEP accepted men's 'risky' sexual behavior, women's experiences with PrEP often were framed in the context of responsibility and 'risky' behavior was a barrier rather than a gateway to access.

**Conclusion:** To avoid missing crucial opportunities for HIV prevention in the future and make PrEP messaging more inclusive, similar campaigns must think more broadly about what constitutes 'risk' for HIV and implement these definitions from the beginning.

KEY WORDS: HIV; New York; PrEP; risk; women.

## Riassunto

**Introduzione:** Quando il farmaco Truvada venne approvato per l'uso come profilassi pre-esposizione per la prevenzione (PreP) dell'HIV nel 2012, esso è stato osannato come la prima importante scoperta in decenni per la prevenzione dell'HIV ed un passo importante per raggiungere l'obiettivo di mettere fine a questa malattia infettiva. Tuttavia, preoccupazioni rispetto ad un equo accesso alla PreP sono state subito espresse. Questo articolo analizza i modi in cui una campagna di sanità pubblica su larga scala ha formulato i messaggi sulla PreP in modo differente tra uomini e donne, e suggerisce un ripensamento più inclusivo di come il rischio dell'HIV viene concepito.

**Metodi:** Questa analisi si basa su 14 mesi (Ottobre 2014 – Dicembre 2015) di ricerca etnografica condotta nel contesto della campagna effettuata a New York chiamata "Ending the Epidemic". L'osservazione dei partecipanti è stata condotta presso meeting pubblici ed eventi correlati a questa campagna; 37 interviste qualitative semi-strutturate sono state condotte con i diretti partecipanti della campagna, così come con i membri delle comunità interessate. L'analisi ha incluso anche una revisione dei documenti correlati alla campagna, come report, articoli di giornale e post di blog.

**Risultati:** Alcune donne importanti coinvolte nella campagna hanno percepito che la campagna fosse stata condotta in misura maggiore dagli uomini nei primi giorni. Mentre i messaggi dati dalla campagna sulla PreP accettavano i comportamenti sessuali a rischio degli uomini, le esperienze sulla PreP delle donne spesso venivano formulate nel contesto della responsabilità ed i comportamenti rischiosi erano una barriera piuttosto che una via di accesso.

**Conclusioni:** Per evitare di mancare delle cruciali opportunità di prevenzione dell'HIV in futuro e rendere i messaggi sul PreP più inclusivi, simili campagne devono pensare in modo più ampio a quello che costituisce il "rischio" di HIV e dovrebbero implementare queste definizioni fin dall'inizio.

### TAKE-HOME MESSAGE

*In order to improve access for women and other populations often over-looked for PrEP programming in the U.S., policymakers and public health workers must expand their definition of who is 'at risk' for HIV.*

**Competing interests** - none declared.

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## INTRODUCTION

When the U.S. Food and Drug Administration approved the drug Truvada for use as pre-exposure prophylaxis (PrEP) to prevent HIV in 2012, it was lauded as the first major advance in HIV prevention in decades and a major step toward reaching the goal of ending the epidemic. However, as has historically been the case with HIV treatment [1], concerns around who would be able to access the drug and under what circumstances arose quickly. While women in areas of high HIV prevalence tend to make up a larger percentage of the population living with HIV than men [2], women in the U.S. historically have been less affected by the virus. Still, certain sub-populations, such as transgender women and women of color, have long been at relatively high risk for contracting HIV, particularly when compared to their cisgender and white counterparts [3, 4]. Despite many efforts to increase attention to these populations women, and particularly Black women, are severely underrepresented in PrEP research and programming [5]. This paper analyzes the ways in which messaging around PrEP was framed during the initial phase of a large-scale public health campaign: New York State's Ending the Epidemic (ETE). It pays particular attention to the differences between messages directed at women and those directed at men with a focus on the role that perceived risk played in either creating or denying opportunities for access to PrEP based on gender. Since research was conducted, at the urging of activists and campaign organizers ETE has directed more attention to reaching women with PrEP messaging and has adopted an expanded understanding of risk.

### *Literature Review*

#### *PrEP's Gendered Associations*

Since early studies supporting oral PrEP's efficacy focused primarily on men who have sex with men (MSM) [6, 7] and less successful trials among women have regularly blamed the women themselves for their failures [8],

PrEP's association with particular gendered identities and sexual orientations has been clear from the beginning. Indeed, much of the science produced around PrEP continues to focus on men almost 10 years later, particularly in the Global North [9]. This repeats patterns established early in the epidemic, when HIV treatment research was conducted primarily among men and physicians consequently faced challenges diagnosing and treating HIV among women as a result [10].

In large part, the rush to build an evidence base around HIV prevention and treatment in MSM in the first decades of the epidemic was a response to the population most significantly affected by HIV/AIDS in the early years: white MSM living in North America. Not only do the numbers from the time show the devastation wrought on this particular segment of the population [11], but survivors testify to the horror of losing friends on a daily basis in multiple documentary sources produced in the ensuing years [12, 13]. However, the public health response to the epidemic in these early years was not a response only to the raw numbers, but to the men themselves, who were notable for their ability to gain credibility as lay experts. In addition to their gender and race privilege, this lay expertise helped many men affected by HIV influence shifts in policy around AIDS drug testing that opened clinical trials to more participants and sped up delivery timelines [14].

White MSM therefore came to be considered a population 'at risk' for HIV, among other 'risk' populations, such as intravenous drug users, Haitians, and hemophiliacs. In cruder terms, these populations often were referred to as homosexuals, heroin addicts, Haitians and hemophiliacs, or the '4 H's' [15]. However, these characterizations of risk populations understandably have been critiqued for their stigmatizing nature [16], as well as for excluding other populations that are vulnerable to HIV [17]. While contemporary HIV research is conducted with an expanded understanding of what constitutes risk, the skewed legacy of this research remains.

### *Gender, risk and responsibility*

As most advocates and healthcare providers who are familiar with PrEP will say, PrEP is not necessarily for everyone, but for those who are 'at risk' for contracting HIV. And perceived risk often is associated with gender. Men often are thought to be more sexual than women and to maintain an increased level of sexual interest and ability during the course of their entire lives. This is evidenced, for example, by the popularity of drugs like Viagra [18].

Since men have social permission to be sexual in a way that women do not, they also are seen as sexual beings who are more willing than women to take risks or make 'bad' decisions to fulfill their desires [19]. As a result, sexual risk is associated with men more often than with women. A blog post from August 23, 2016 by the Sophia Forum, an advocacy organization for women living with HIV in the UK, illustrates this point well. Responding to a series of social media conversations around women and PrEP, the Sophia Forum board wrote:

*"Somehow there appears to be little space to even consider the notion that women may also be risk takers [...] risks are enjoyed across the board. But according to the current dialogue apparently women do none of these things; we have safe sex and take few if any drugs [...] Sophia Forum wholeheartedly supports the introduction of PrEP, but we feel we cannot stand by and watch as women are denied the right to own their own risk"* (Sophia Forum 2016; emphasis my own).

As this post points out, when it comes to discussing PrEP, and even sex in general, women (with the exception of commercial sex workers [21]) are not allowed to be risky. And if risk isn't recognized, then opportunities to reduce HIV transmission are diminished.

Scholarship on the human papilloma virus (HPV) vaccine, an obvious parallel to PrEP, demonstrates how a drug can be used to deepen inequalities by denying the right to sexuality and risky sex along gendered lines. In this case, the HPV vaccine was framed by

pharmaceutical companies and by the media as protection against cervical cancer in an attempt to de-couple the vaccine from its associations with a sexually transmitted infection [22]. De-sexualizing the HPV vaccine is particularly important because it initially was released only for young women and girls and, following historically gendered scripts, advertisements for the vaccine framed these populations as vulnerable to sex, rather than as conscious sexual beings [23]. Although the vaccine has since been approved for young men, this early framing exhibited a 'double standard' when it comes to the sexuality of young women versus young men [24], thereby creating the idea that young men are not 'at risk' for HPV in the same way that young women are [25]. Ironically, there is a built-in assumption in all of the vaccine advertising that women get HPV through heterosexual contact with men, who are the actual vectors of transmission. Women must therefore receive the vaccine on behalf of their male partners, who are absolved of responsibility and whose sexual desire is upheld as legitimate. This assumption that women should bear the responsibility of protecting both their own sexual health and that of their partners is highlighted in the literature on The Pill as well [26]. Further, the very existence of drugs like Viagra for men and accompanying advertisements that send messages of virile masculinity emphasize that men *must* be sexual, and when they are not, this condition can be treated with pharmaceuticals [27]. Men can be treated for too little sexual desire while women are treated both for male desire and for having too much sexual desire themselves.

### **METHODS**

#### *Study design and procedure*

This article is based on 14 consecutive months (October 2014 – December 2015) of ethnographic fieldwork following government workers, HIV/AIDS service providers, academics, advocates, and community members involved in New York State's ETE campaign. The research included 37 semi-structured

qualitative interviews, participant observation at dozens of meetings and events related to ETE, and document review. Governor Andrew Cuomo announced the state's intention to launch a campaign to end the AIDS epidemic at New York City's Gay Pride Parade in June 2014. That October, approximately 60 prominent HIV/AIDS service providers, academics, advocates, and community members from across the state were convened to form the Ending the Epidemic (ETE) Task Force. Led by the (now former) Director of the New York State Department of Health's AIDS Institute, Dan O'Connell, and Charles King, a leading AIDS activist from New York City, the Task Force met monthly from October 2014 – January 2015 to develop a Blueprint to bring AIDS cases below epidemic levels in New York State by 2020. The Task force compiled and structured recommendations generated both internally and through an online survey into the Blueprint according to the three priority areas announced by Governor Cuomo in June: identify persons with HIV who remain undiagnosed and link them to health care; link and retain persons diagnosed with HIV to health care and get them on anti-HIV (antiretroviral) therapy; facilitate access to PrEP [28]. This article focuses on early campaign-related activities (e.g. marketing campaigns, panel discussions) designed to address the third point of the Governor's plan regarding facilitating access to PrEP.

It is important to note that it was sometimes hard to define exactly which activities count as part of the campaign; in some respects, as interviewees pointed out, ETE began long before the campaign itself was devised. Data collection therefore followed formal ETE-related events and activities that claimed affiliation as much as possible with some attention to other activities carried out by key actors (both institutions and individuals) in the campaign.

### *Study participants and sampling*

Data were collected through formal, semi-structured interviews, participant-observation, and document review. In total, formal

interviews were conducted with 37 people either directly associated with or affected by the Ending the Epidemic campaign. Interviewees were sought out and purposively sampled [29] based on either their position within the campaign (e.g. Task Force members) or their potential to be affected by it (e.g. transgender women). When seeking out community members who might be affected by the campaign, people were approached who already worked in the HIV/AIDS field in some capacity and who were either known to represent a group of particular interest to ETE organizers, or who spoke up in an ETE-related meeting or event to express a strong opinion about the effects of the campaign on the community they felt they represented. In some cases, populations that were a key focus of the study (e.g. women) were over-sampled. The final sample included government workers, HIV/AIDS service providers, academics, advocates, and community members involved in or affected by ETE.

Interviewee demographics are displayed below in Table 1. It should be noted that, because Task Force members were drawn from a variety of field, these interviewees were counted twice; first as a Task Force member and second according to their field.

### *Study instruments and measures*

Interviews were conducted using a semi-structured guide that was adapted to respond to the differing roles of the interviewee. Questions included interviewees' perceptions of what it meant to "end" the AIDS epidemic, how they would describe their personal experience as part of the ETE campaign, their perceptions of how PrEP was mobilized through ETE, and how they expected the campaign to move forward.

### *Ethical aspects*

The researcher received initial approval for the study from the Hunter College Institutional Review Board on December 29, 2014. Data collection conducted prior to this date (October – December 2014) consisted of attendance at meetings and events that were

**Table 1.** Interviewee demographics.

Gender Identity		
	Female	14
	Male	20
	Transgender	1
Race		
	Black/African American	10
	Latinx	5
	White	16
	Asian	2
	Unknown	1
Role		
	Task Force Member	16
	Government	7
	Health Service Provider	19
	Researcher	6
	Activist	9
Person Living w/HIV/AIDS*		4
*Publicly self-identified		

open to the general public, which therefore did not require IRB approval. All names used in this article are pseudonyms to protect the participants' privacy.

### *Data analysis*

Interview recordings were transcribed and coded by the researcher using Atlas.ti, a widely-used qualitative analysis software package. An inductive thematic approach to coding and analysis was used in which codes were derived from the data and refined over time as new themes emerged. Participant-observation notes, popular press articles, public marketing campaigns run by government entities and NGO's operating in and around New York City, and email listservs run by both government entities and prominent AIDS activist organizations were similarly reviewed for common themes.

## **RESULTS**

While campaign messaging around PrEP accepted men's 'risky' sexual behavior and framed this behavior as a reason why men should have access to PrEP, women's experiences with PrEP often were framed in the

context of responsibility and 'risky' behavior was a barrier rather than a gateway to access.

### *Sexual risk-taking is expected among men*

Messages circulating through the ETE campaign demonstrated a high level of comfort with men's sexuality, especially among MSM, and an expectation that men be very sexually active. At numerous meetings and events related to ETE, references were bandied around pertaining to male genitalia and sexual acts between men, such as referring to the inaugural meeting of an ETE-related initiative as the 'flaccid launch'. During a downtown community PrEP panel for which several NGO's and community groups had partnered with the New York City Department of Health and Mental Hygiene one presenter, a young MSM of color named Julio, spoke boldly about his many sexual exploits. Julio's voice was strong and loud, complemented by gesticulations, while he shared details of his experiences seeking sexual partners and discussing HIV risk and PrEP with them. Taking a similar tone, another man then stood up in the audience during the Question and Answer period and read aloud a string of messages

about PrEP he had exchanged with a man he had met on a hookup app.

In addition to the rhetoric that arose spontaneously during the campaign, materials produced in the context of ETE similarly promoted the message that men's sexuality was an acceptable topic for public conversation. For example, in mid-2015 a marketing campaign for PrEP spread across upper Manhattan. This campaign featured a black man sticking out his tongue to display a blue PrEP pill with the tagline 'Swallow this' underneath. In meetings with the sponsors, I learned that the campaign was specifically meant to be 'provocative' by sending a sexual message targeted at MSM of color and aligning this message with access to PrEP.

Conversely, references to women's genitalia and sexuality were practically nonexistent in the early days of the campaign, and women who participated in ETE-related events rarely mentioned their own sex lives. As one trans woman, Joan, noted toward the end of the community session mentioned above: *some groups aren't allowed to brag about sex*. Although she did not elaborate on this statement, Joan's statement implied that she did not feel at liberty to discuss her own sex life, in contrast to others on the panel.

Further, some women suggested that there was not just silence around women's sexuality in the campaign, but that women's voices felt underrepresented in the organization of the campaign overall and women rarely felt comfortable speaking up in general. When describing her experience as a woman on the ETE Task Force, Frankie said:

"There were times when I was a little frustrated because there's clearly a good old boys club that still exists. There were frustrating things that happened [...] whose opinion got validated. Whose opinion didn't. Whose comments got shut down. And I'm not trying to be ugly, it's just [...] patriarchy was in the room".

Frankie went on to note that one of the other women on the Task Force came up to her after the first meeting and asked if they could get together to talk. Once they managed to

meet for brunch, Frankie remembered asking: "Why did you wanna talk to me?" And I didn't let her answer, I said, "Is it cuz I was one of the very few women in the room and I, like, said shit and you were like 'Wow, who's that?'" And she was like "Yeah, pretty much".

### *Women emphasized their responsible sexual behavior*

When women did discuss their own sex lives and their experiences with PrEP, they often appeared reluctant to frame their behavior as 'risky' and instead emphasized that they were being responsible by choosing to take PrEP. Dahlia provides a good example of the interplay between risk and responsibility for women trying to access PrEP. Speaking at a community event in upper Manhattan, Dahlia told the audience she had used PrEP to become pregnant with her HIV-positive husband and explained that she had done extensive research before approaching her doctor for a prescription. However, her doctor refused to prescribe PrEP, saying that she wouldn't condone Dahlia's 'risky' behavior. Dahlia expressed her frustration, saying: "*I really was looking for [my doctor] to reduce and to minimize the risk to myself, and she kind of left me dangling with that*". In this way, Dahlia stressed that she was trying to be responsible and take care of herself, but her doctor stood in the way because she viewed Dahlia's behavior as risky.

Another speaker on the same panel, Sharon, spoke of her experience as a single woman who practiced polyamory. Sharon contrasted her experience with Dahlia's by noting, "*I don't have the same family-positive, moving story*", as though apologizing for her story of polyamory. Sharon went on to note that she was part of a "*whole network of exposure*" and was therefore very conscious of taking care of her sexual health. In contrast to Dahlia's experience with her physician, Sharon noted that her healthcare provider commended her for seeking out PrEP and told Sharon that "*she wished other patients were as cold-blooded about their risk assessment as I am*".

Similarly, at the downtown community PrEP

panel, a trans woman of color named Jasmine noted that she was on PrEP because she had been in a series of relationships in which she wasn't sure if her partner was sleeping with other people. Starting PrEP was a way for Jasmine to protect herself just in case. Throughout the event, Jasmine was relatively quiet compared to the cisgender men with whom she shared the stage, a notable contrast to the bold claims her fellow panelists like Julio made about the number of sexual partners they had recently had. Instead, Jasmine emphasized her own vulnerability in relationships in which she felt she had little control. As a trans woman of color, Jasmine was indeed particularly vulnerable compared to her co-panelists [4], and PrEP was a way for her to mitigate the risk she felt was forced on her through her romantic relationships.

### *Risk is relative and varies according to individual experience*

As women participating in PrEP-related events continually confirmed, there was far less information being disseminated to women about PrEP and less support for those using the drug. Speaking of her own experience learning about PrEP, Sharon said:

“When I found out that such a thing as PrEP existed, which I only found out this summer [...] Of my female friends, only one person had heard that there was a drug that could prevent HIV. All my gay male friends knew about it [...] and of my straight male friends, only one knew that this existed [...] and my friends are for the most part a well-educated and sex-positive bunch”.

Frankie confirmed Sharon's sentiments, noting, “*PrEP, you know, has a very very kind of male gay-centric kind of focus*”.

However, as a number of women pointed out, risk is both relative and individually assessed. Talking about an interesting discussion held during the PrEP panel for women, Frankie noted that one woman in the audience made the point that sexual identity is not always tied directly to risk. Rather, “*people make assumptions about people in their sex lives by, you know, like: - Oh, why would a lesbian be at*

*risk for HIV? Well, you're making assumptions around risk based on somebody's sexual orientation*”. Further, Dr. Luz, who primarily works with Caribbean populations in Brooklyn, spoke about the way that her patients weigh risks as women of color and how she perceives the benefits of a technology like PrEP for this particular population:

“Someone comes in asking me for PrEP and they don't really have that much of a risk, and this is [...] true in serodiscordant relationships where the partner, who I may be taking care of, has been undetectable for a really long time. There really isn't a clinical reason for them to be on PrEP. But, it allows them this sense of control over their sexuality and ability to be intimate in a way that I think this population in particular deserves to have. And I think that that has value in itself”.

## DISCUSSION

While fostering a level of comfort with a wide range of sexual practices and preferences has been one of the great achievements of AIDS activism, not all populations have benefitted equally from this greater acceptance of 'risky' sexual behavior. In the early stages of the ETE campaign, sexual risk was seen as an entry point to PrEP for men and particularly MSM. At the same time, the little messaging directed at women suggested that women should be 'responsible' for their health and not engage in the 'risky' behavior that would make them a candidate for PrEP. This made risk a barrier rather than an access point. As previously outlined in a blog post derived from this research [30], this messaging was built on gendered stereotypes of risk and responsibility, and reflect longstanding challenges to accept that women take sexual risks, being just as 'irresponsible' as men. And indeed, when filtered by sex, the ETE Dashboard site that tracks PrEP uptake among Medicaid recipients shows a large and growing gap in uptake of PrEP among women as compared to men through the end of 2018 (<http://etedashboardny.org/data/prevention/prep-nys/>). This growing gap suggests that women were not adequately targeted with PrEP messaging

during the early years of the campaign. It is therefore important to both recognize and legitimize women's right to risk, but also to recognize that risk and responsibility are not mutually exclusive. As noted by Dr. Luz, women's realities, and particularly those of women of color and transgender women, are molded by multiple intersecting power differentials that shape risk and responsibility differently than they do for men. Anthropologist Rayna Rapp, among others, has suggested that risk is relative and contingent, and that each individual health risk must also be weighed against a person's risk of, for example, losing their housing or their income [31]. In this context, a woman's decision to start PrEP should be viewed as a responsible choice at the same time that her sexual choices may appear risky and any 'risks' should be acknowledged as a legitimate entry point to PrEP as it is for men.

As discussed above, direct involvement in research and policymaking on the part of people living with and affected by HIV is another important legacy of AIDS activism. ETE has been no different in this regard. It is to the credit of both those on the community activist side as well as those sitting formally in the AIDS Institute that these early gaps in reaching women were quickly identified and a formal advisory group formed to address them. This advisory group developed a set of recommendations that addressed the disproportionate burden of HIV on women of color and transgender women, and the intersecting risks these populations face [32]. An activity report generated by the AIDS Institute in 2019 suggests these recommendations were

heeded with reported ETE-related activities ranging from developing messaging around PrEP for women to providing technical assistance around PrEP at reproductive and maternal health organizations [33]. However, given the widening gender gap in PrEP uptake there is much catch up work to be done and it remains to be seen how effective these programs will be. To avoid missing such crucial opportunities for HIV prevention in the future, similar campaigns must think more broadly about what constitutes 'risk' for HIV and implement these definitions from the beginning.

## CONCLUSION

In conclusion, risk for HIV is relative and contingent. Populations such as women and people of color have long been underrepresented in HIV prevention research and programming in the U.S., because they do not fit the historical definition of a population 'at risk'. In order to reach these populations with timely and effective prevention options, such as PrEP, public health campaigns must recognize a more expansive definition of risk and adjust messaging and programming accordingly.

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