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## Review

# Assessing PrEP messaging and communication: A review of the qualitative literature

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**Abstract**

Pre-exposure prophylaxis (PrEP) is a biomedical HIV prevention intervention approved by the FDA in 2012. Nevertheless, most sexual minority men (SMM) who could benefit from its use are not currently prescribed PrEP. The literature during the first decade of PrEP availability has suggested a diverse set of multi-level barriers and facilitators to PrEP uptake and adherence. Through a scoping review, 16 qualitative studies were surveyed to assess these barriers and facilitators, specifically regarding messaging and communication. Seven main themes were identified: *information & misinformation, peer messaging, expansion of sexual experiences, relationships with providers, expectations & stigma, navigation support, and barriers to uptake & adherence*. Data suggest that peer support, messaging around empowerment and agency, and PrEP's role in shifting sociosexual norms contributed to uptake and adherence. On the other hand, stigma, provider disconnection, and access issues hindered PrEP uptake and adherence. Findings could inform multi-level, strengths-based, and holistic approaches to designing effective interventions for PrEP engagement among SMM.

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PrEP, Sexual minority men, HIV, Messaging, Qualitative research.

**Introduction**

Pre-exposure prophylaxis (PrEP) is a biomedical intervention that has been approved for HIV prevention in the USA since 2012 [1]. However, estimates suggest that roughly 10% of Americans vulnerable to HIV infection are actually utilizing PrEP [2,3]. In addition,

although Black and Latino sexual minority men (SMM) are disproportionately vulnerable to HIV infection, they only account for 10% and 12% of PrEP prescriptions, respectively [4]. A confluence of social, cultural, and structural factors presents as barriers to PrEP uptake and adherence, particularly among ethnically and racially minoritized groups. These barriers manifest in the form of perceived and experienced financial burdens to PrEP access [5], disconnection with providers [1], and social and peer stigma [6], among others. Conversely, research suggests that demographic and social features such as youth, higher education, and income [7]; sexual behaviors and literacy [5]; and engagement across social and virtual networks [8] may serve as facilitators to PrEP uptake and adherence. Notably, the extant literature points to the role that both institutional messaging and peer communication have in the knowledge production and management that SMM develop with regard to their relationship to PrEP.

The current review aims to identify barriers and facilitators to PrEP uptake and adherence among SMM in the USA, during the first decade of its availability. These barriers and facilitators will focus on the ways that knowledge was produced, shared, and internalized by SMM during this early rollout period. Through a scoping review, the current review will assess qualitative research to provide more nuanced understandings of the processes and mechanisms that hindered and promoted PrEP uptake and adherence among this high-priority population.

**Scoping review**

To achieve the review's aim, a scoping review was identified as a suitable procedure to assess the literature. A scoping review is a "form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically searching, selecting, and synthesizing existing knowledge" [9], pp. 1292–1294). Scoping reviews offer the opportunity to rapidly map out key concepts that are imperative to assessing broad topics and are particularly useful in identifying gaps in the literature, as well as extracting the essence from complex bodies of knowledge [10]. [11] identified five steps that have remained consistent across evolving iterations of scoping reviews.

These consist of the identification of the research question(s), relevant studies, the selection of the studies, the charting of data, and the collating, summarizing, and reporting of results. The review's aim is to identify barriers and facilitators to PrEP uptake and adherence among SMM in the USA, during the first decade of its availability. Utilizing the University of Illinois Chicago's online library database, the following keywords were used to search for relevant studies: "pre-exposure prophylaxis" AND "gay" OR "bisexual" AND "qualitative" AND "united states". The search was limited to articles in peer-reviewed journal published between January 1, 2012 and July 28, 2022. After ensuring that all articles fit the inclusion criteria, a final set was selected as the review's sample. Each article was subject to a close reading to identify its most salient themes. These themes were then grouped into categories befitting of the patterns observed across the sample and organized in order of those most to least represented in the sample. In addition, quotes that were illustrative of these final themes were selected to showcase the findings more comprehensively.

## Findings

The database search resulted in 523 articles. After confirming for inclusion criteria, 16 articles were selected as the final sample. Articles that used quantitative and/or mixed methods, whose samples did not primarily consist of SMM, or that were not based in the USA were excluded. After reviewing the 16 articles, seven themes were identified as the most salient ones. Both *information & misinformation* [12–21] and *peer messaging* [16–18,21–26] were featured in nine of the sixteen (56%) articles. *Expansion of sexual experiences* [12,16,18–20,22,25] was the next most salient theme, presenting in seven of the sixteen articles (44%), and was closely followed by *relationships with providers* [13,15,17,20,21,23], which was alluded to in six of the sixteen (38%) articles sampled. Both *expectations & stigma* [16,18,21,24,26] and *navigation support* [18–20,22,27] were signaled in five of the sixteen (31%) articles surveyed. Lastly, *barriers to uptake & adherence* [13,14,17,23] was exemplified in four out of sixteen (25%) of the sample of articles.

### Information and misinformation

One of the review's most salient themes, *information & misinformation*, referred most specifically to the sources and nature of information regarding PrEP, in particular, during the early stages of rollout. There were many instances in which SMM alluded to information around PrEP's effectivity, as well as potential side effects. In addition, this theme addressed the need for more education on the subject, while also indicating gaps in access to consistent knowledge around this nascent biomedical intervention. Many of the expressions regarding how SMM found out about PrEP came from

succinct, straightforward exchanges in often quotidian situations:

*"I know that it's a pill and people take it. There's some friends I know, acquaintances, that I'm the designated driver for all the time so I bring them places and they told me they were on PrEP and that it was easy, they felt safer now."* [14]

Accounts such as this exemplify how a lot of the knowledge that was available to SMM during the earlier stages of its availability came mostly from peers and was presented in an accessible, matter-of-fact manner. The context and nature of this type of messaging underscore the importance of peer networks well-equipped to share knowledge and bridge gaps between the community and the institutions that serve them.

### Peer messaging

The next theme, sharing the same level of saliency, was *peer messaging*. This theme accounted for a diverse set of features, including agents, context, and outcomes. For instance, accounts consistent with this theme often made reference to communicating about PrEP with friends, romantic and sexual partners, and relatives. Additionally, some instances referred to exchanges taking place in both physical and virtual settings. Further, many of this theme's exemplars alluded to how this type of messaging should center a level of responsibility to one's communities:

*"The benefits that I've gained from using PrEP is being part of a larger movement and recognizing that me doing this is hopefully, actively going to benefit the entire gay community. By me being on it and spreading the word of PrEP and spreading the message of how beneficial PrEP is and encouraging others to get on it, that hopefully they do the same and that this could be some sort of larger effect, where we now are more protected as a community"* [22]

Narratives along these lines underscore the impetus driving many SMM's decision to speak freely and openly to peers about PrEP, which was primarily to promote a greater, communal good. Many SMM referenced in these studies suggested that they were often taking on informal roles as health educators, given the barriers that many of their peers faced in accessing these more formal settings. Nevertheless, these men's motivations were diverse in nature.

### Expansion of sexual experiences & relationships with providers

The next theme in this analysis is the *expansion of sexual experiences*, wherein the texts broadly referenced changing sex norms among intergenerational samples of SMM. These changing norms often centered around sex positivity, agency in sexual decision-making processes, and how the two contributed to evolving sociosexual identities. In addition, the advent of PrEP also shifted

perceptions around HIV, in particular, the ways in which HIV-negative men viewed sex and relationships with their HIV-positive counterparts. Moreover, many men made reference to ways in which PrEP use and communication provided a sense of empowerment, as well as reducing generations-long sexual anxieties:

*“For me, [taking PrEP] was, for the first time, a way that I could actively protect myself with it all being my responsibility—and not being dependent on someone else telling me what they were doing in terms of protecting their selves or their status. So, it was a way for me to take the other person out of the equation almost entirely, and put all the responsibility on me ... in terms of keeping myself protected.” [19], p. 152)*

This sense of responsibility, despite being presented in an individual manner, still highlights the ways in which SMM enter into these decision-making process embodying knowledges consistent with their engagement with social, cultural, and structural scripts. This is particularly the case with regard to the next theme, *relationships with providers*. When addressing this theme, many respondents signaled to facing difficulties disclosing their sexuality and sexual behaviors with providers lacking an affinity with SMM. They also made note of providers who either lacked information regarding PrEP or were resistant to prescribe it. The following quote addresses the issue of difficulties with disclosure:

*“If doctors make me uncomfortable for being gay, then the last thing I want to do is tell you about my sex life ... There are a lot of doctors who throw their own personal opinion into their perspective. One asked me if I’m homosexual. That made me uncomfortable.” [15]*

It is important to note, however, that not all SMM in these studies made negative references to their health care providers and the relationships they had with them. Some, in fact, identified them as their initial sources of PrEP information, as well as credible figures that legitimized its use. Nevertheless, experiences and expectations of stigma oftentimes truncated SMM’s capacity to meaningfully engage in PrEP use.

### Expectations and stigma & navigation support

The theme of *expectations & stigma* expands on this subject. Specifically, this theme referenced positive, negative, and ambivalent attitudes about PrEP and PrEP users, as well as stereotypes about the latter. There were also several references to moral values around who deserved to be on PrEP, such as those in serodiscordant relationships and younger SMM. Ultimately, a lot of these competing attitudes and beliefs created tension and othering among SMM:

*With the whole PrEP thing that was the problem with being a “PrEP whore.” Then which went from a positive approach where everyone should be on PrEP for safety and to protect*

*themselves and their partners and whoever they have sex with went to a new term to be created with “PrEP whore.” Everyone was now in two deciding teams of pro-PrEP and con-PrEP. It was a huge mess, you could see it in the apps, it was all over: “All PrEP whores, stay away.” “On PrEP, ready to bareback, breed me. Give me your seed.” All kinds of shit. It was just alarming. Cuz I was just like, “Wow.” This medicine which was supposed to benefit us is now being questioned.” [16]*

The novelty of this biomedical intervention, in concert with discrepant knowledge and messaging, contributed to negative labeling and stereotyping which diminished PrEP’s promise as the central feature in many SMM’s sexual health repertoire. To that point, the theme of *Navigation* support represents accounts regarding PrEP as being part of an expanded sexual health toolkit that aligned with values around harm reduction, risk assessment and management, and other strategies to normalize its use. Further, PrEP use was acknowledged as a way to more intentionally engage in broader health care:

*“Before this, I wasn’t getting tested for every other STD on a regular basis unless I had some kind of symptom ... I wasn’t going in and saying, “Hey, would you test me for syphilis and gonorrhoea and chlamydia?” ... But now I’m regularly tested, so I feel much more confident that ... I’m not passing along anything. [19], p. 153)*

### Barriers to uptake and adherence

Given that, historically, SMM have faced many barriers to actively and equitably participate in medical institutions, the potential that PrEP use has to promote more successful engagement should be noted. Finally, the theme of *barriers to uptake & adherence* addresses more intentionally the material barriers to PrEP use, such as cost and the necessity to meet other basic needs:

*“Definitely how confusing the pricing and what other programmes are available to supplement insurance, because you can price PrEP on my insurance website, and it comes out so expensive. And then the PrEP assistance programme, all of it is so confusing and vague, I’m not sure how much I will actually end up paying for it.” [13]*

It is imperative to note how confusing PrEP enrollment may feel for many SMM, even during later stages of its rollout. When considering whether using PrEP is ideal, SMM must consider how it may fit within their broader hierarchy of needs, thus having access to accessible messaging and coverage that is consistent with their holistic experience should be paramount to proceeding enrollment and retention efforts.

### Conclusions

The goal of this review was to identify and assess the barriers and facilitators that impacted PrEP uptake and retention during its first decade on the market.

Particularly, this review sought to underscore the importance of messaging and communication in these processes. Findings highlight several key features that could inform more effective PrEP enrollment and retention efforts. For instance, information needs to be accessible, both in terms of availability and clarity. This process may be aided by the recruitment of peer-led efforts to share information and by centering the importance of achieving communal wellness to the message. Further, messaging should underscore the potential of PrEP use to enhance feelings of sociosexual agency and empowerment among SMM. In addition, the process might benefit from reframing providers' gate-keeping roles to be more responsive of the unique needs of SMM. Moreover, it is important to also attend to remedying pervasive negative attitudes within the community of SMM, such that the aforementioned empowerment efforts may succeed. Finally, PrEP should be presented as part of a broader sexual and overall health repertoire that addresses the holistic needs of this population.

This review counts with some limitations, mainly the small sample size, as well as only featuring the lived experiences of SMM and doing so exclusively in the context of the USA. A more in-depth exploration of these topics should intentionally center features of SMM's diverse lived experiences, such as race and ethnicity, age, and class, among others, particularly in efforts to address HIV prevalence disparities among racially and ethnically minoritized SMM [15,20–22].

Despite these limitations, this review contributes to the literature by underscoring the importance of both peer and provider efforts to successfully communicate PrEP's effectivity for SMM. These findings could inform interventions that address multi-level barriers from a strengths-based perspective, attending to SMM's needs in a holistic manner. Inviting a cross-generational, life course-oriented approach would also strengthen intervention efforts by invoking lessons from SMM who experienced harsher iterations of the AIDS epidemic, while also honoring the unique conditions of SMM who came of age in a post-PrEP world [13,16,23,26]. Providers' perspectives should also be centered in these intervention efforts, given that data suggest that their authority and expertise may positively contribute to PrEP uptake and retention efforts [23]. In a recent article, colleagues and I [28] suggest that PrEP uptake has the potential to serve as a new social movement among SMM, similarly a digital article [29] in the popular media LGBT publication *them* notes that the next decade of PrEP needs to improve upon its first, because “when it comes to health care, marginalized communities' liberation is only possible if other at-risk communities are given equal access to, information about,

and agency over the medication in its second decade.” Thus, any effort to empower SMM needs to both address their history and equitably support the members of this heterogeneous population whose intersectional identities have removed them from conversations and experiences of optimal well-being.

### Conflict of interest statement

Nothing declared.

### Data availability

No data was used for the research described in the article.

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