

A research briefing

PrEP, sex, intimacy and mental health

Gus Cairns | September 2020



“Sexual Health is a state of physical, mental and social well-being in relation to sexuality,” declares the World Health Organization.¹ In other words, sexual health is about a lot more than the treatment and avoidance of sexually transmitted infections and other health issues related to sex such as pregnancy.

True sexual health includes being *at ease* as much as possible with sex, that most taboo, conflicted and potentially dangerous of life’s activities, but also the one that brings us some of life’s greatest rewards – connection, love and a sense of one’s own value.

The socially disadvantaged, those who violate some societies’ norms in their sexual behaviour (such as unmarried women or sex workers), people whose sexual desires conflict with their gender roles (such as gay men) or those who have in the past experienced sexual violence may be perfectly healthy physically with regard to sex, but subject to deep unease, sadness or conflict that casts a shadow over their sex lives.

Add in a potentially fatal disease that may feel like a punishment for their sexual desires and acts, and it is no wonder that people with HIV or who belong to groups threatened by it have much higher rates of depression or anxiety than the general population.

¹ World Health Organization. *Defining sexual health report of a technical consultation on sexual health*. WHO, 2006.

For instance, a systematic review of studies of mental health in lesbian, gay and bisexual people² found that major depression was at least 50% more common in LGB people and that suicide rates were particularly elevated. A European study³ found that the presence of anxiety disorders was twice and that of major depression three times greater than the rates found in general-population studies⁴. Rates of depression and anxiety are even higher in people living with HIV.

“ There is no doubt that the risk of HIV impacts on the social wellbeing of even many otherwise advantaged gay men.”

Given the anxiety caused by fear of HIV in those who already have it, it is not surprising if fear of *acquiring* HIV also adds to the burden of poor mental health in those who don't. Several studies have shown a direct correlation between sexual risk behaviour and poor mental health in gay and bisexual men.

For example, in a 2004 study⁵, the likelihood of gay men having had sex defined as risky for HIV with at least one of their last four sex partners was 7.1% among men without socio-psychological health problems (such as depression, polydrug use, intimate partner violence, and a history of childhood sexual abuse); 11% with one of those problems; 16% with two of them; and 22.5% with three or four. The likelihood of them already having HIV was also strongly related to their psychosocial history.

This and similar studies gave rise to the idea of a 'syndemic' of HIV, psychological poor health and social disadvantage among gay men. This term has been used to describe the way that pre-existing trauma, anxiety and depression, condomless and casual sex, chemsex and other drug use, the stigma of HIV itself, and societal disadvantage may all combine to greatly amplify the risk of HIV infection for certain members of already at-risk populations – and how that risk may then contribute to keeping the syndemic going. It explains why certain members of certain populations may be much more likely to risk and catch HIV than others but also implies that it may be very difficult to break the vicious circle that may lead to HIV infection (or to other problems such as addiction).

There is no doubt that the risk of HIV impacts on the social wellbeing of even many otherwise advantaged gay men. Professor Sarit Golub, a social scientist at Hunter College in New York who has written widely on HIV anxiety in gay men and motivations to take PrEP, has said that it was a “psychological tragedy” that one of her studies showed that half of gay men thought of HIV all or most of the time during sex.

Golub and other social scientists, however, have also been keen to understand that gay men's HIV risk, and in particular the decisions they make to forgo condom use, are not only due to trauma and poor mental health. It is also important to recognise that gay men may not only be running away from negative experience if they have sex that risks HIV – they may be seeking positive experiences too.

² King M et al. *A systematic review of mental disorder, suicide, and deliberate self-harm in lesbian, gay and bisexual people*. BMC Psychiatry, 8: 70, August 2008.

³ Wang J et al. *High prevalence of mental disorders and comorbidity in the Geneva Gay Men's Health Study*. Social Psychiatry and Psychiatric Epidemiology, 42: 414-420, April 2007.

⁴ Bandelow B. *Epidemiology of anxiety disorders in the 21st century*. Dialogues in Clinical Neuroscience, 17: 327-335, September 2015.

⁵ Stall R et al. *Association of Co-Occurring Psychosocial Health Problems and Increased Vulnerability to HIV/AIDS Among Urban Men Who Have Sex With Men*. American Journal of Public Health, 93: 939-942, June 2003. See aidsmap.com/news/report-here.

In one study authored by Golub amongst others, published in 2014 but from data collected from gay men before PrEP was introduced⁶, condom use or lack of it was most strongly associated with, more than any other variable, something the researchers called 'intimacy interference'.

This is the feeling that condoms place an emotional, as well as a physical, barrier between partners and that not using them is related to the need to feel emotionally close to partners. Intimacy interference is different from condoms interfering with sexual pleasure, which was less strongly associated with condomless sex⁷.

“...gay men who experienced high levels of stigma about their sexuality were more likely to adopt condomless sex.”

Interestingly, in this study, gay men who experienced – externally or internally – high levels of stigma about their sexuality were more likely to adopt condomless sex if they believed condoms were a barrier to intimacy than gay men who felt less stigmatised. In other words, gay men who felt more distress about being gay had less feelings of self-efficacy about persevering with condom use if condoms, for them, symbolised distrust and distance rather than the closeness they craved.

In another study published in 2018, but from data gathered in 2013, Kristi Gamarel and Sarit Golub⁸ analysed a feeling called 'relationship discrepancy' in gay men. This is the degree to which people seek validation through their partners and how – either in order to do so or *by* doing so – come to share somewhat similar world views, habits, and interests.

Gamarel and Golub put it this way: “Similar to the ways in which individuals are motivated to reduce discrepancies between their actual and ideal selves, relationship partners are motivated to reduce closeness discrepancies in their relationship.”

High relationship discrepancy implies an uneasy awareness that the relationship falls short of this ideal. Given that sexual intimacy is one way, and maybe the most powerful way, that couples experience a sense of alignment and union, if condoms are experienced as inimical to that sense, then, say Gamarel and Golub, “In this context, closeness motives and prevention motives have been set up to directly contradict each other.” What makes you feel emotionally more secure may put you in physical danger.

Several authors have speculated that PrEP might be able to break the link between condomless anal sex and anxiety about its consequences. Even better, could it strengthen the link between sex and security?

⁶ Starks TJ et al. *Contextualizing condom use: Intimacy Interference, stigma, and unprotected sex*. Journal of Health Psychology, 19: 711-720, June 2014.

⁷ Golub SA et al. *The Critical Role of Intimacy in the Sexual Risk Behaviors of Gay and Bisexual Men*. AIDS and Behavior, 16: 626-632, April 2012.

⁸ Gamarel KE and Golub SA. *Closeness Discrepancies and Intimacy Interference: Motivations for HIV Prevention Behavior in Primary Romantic Relationships*. Personality and Social Psychology Bulletin, 45: 270-283, February 2019.

To summarise:

- > People who are at elevated risk of HIV also tend to suffer from poor mental health, partly because of worry about HIV but also due to other stressors in their lives, including being members of sexual, gender or racial minorities.**
- > There is strong evidence that, as well as protecting people from HIV, pre-exposure prophylaxis also results in improved mental health among people who take it.**
- > The improvements in mental health appear quite specific: the most marked improvements are to anxiety, and specifically to anxieties about acquiring HIV and about people with HIV. Other mental health conditions such as depression are less clearly improved by taking PrEP.**
- > PrEP can bring some anxieties with it, such as fear of being stigmatised as promiscuous or irresponsible, fear of being thought HIV positive, and concern about side effects. However, these tend to act as disincentives to start PrEP, rather than barriers to continuing with it.**
- > Most studies of the effect of PrEP on mental health have been conducted in cisgender gay and bisexual men. There have been a few in cis and trans women and in women who use drugs, but none we are aware of in trans men and none in cis heterosexual men as a separate study population.**
- > What studies have been done so far in cis women suggest is that anxiety about HIV infection via sex is less central to women's experience of health anxiety, and that stressing messages of self-care, autonomy and self-worth may better motivate women to consider PrEP.**

Sex without fear

***Sex Without Fear*⁹ was the title of a 2014 article by gay journalist and novelist Tim Murphy which documented the changes PrEP was making to early adopters of PrEP. Murphy's introductory comment was that PrEP had "the potential to dramatically alter the sexual behaviour—and psychology—of a generation."**

In the article, a gay psychotherapist called Damon L Jacobs – who went on to found PrEP Facts, the 20,000-member Facebook-based information and support group – said: "I'm not scared of sex for the first time in my life, ever. That's been an adrenaline rush."

"I'm not scared of sex for the first time in my life, ever. That's been an adrenaline rush."

However, the piece also reflected how difficult the transition from traditional 'safer sex' and condom use to more mixed and medicalised methods of protection was for some gay men. Murphy commented on how "a drug that can alleviate so much anxiety around sex is itself a source of concern" and found that many friends who had started PrEP only wished to be quoted anonymously, fearing backlash from their own community.

Some feared that PrEP would set off a new wave of sexually transmitted infections – an issue addressed in [another briefing paper](#). But for others, Murphy commented, "The very existence of such a drug is a kind of betrayal: of those who've died in the epidemic; of fealty to the condom, an object alternately evoking fear and resilience, hot sex and safe-sex fatigue; and of a mind-set of sexual prudence that has governed gay-male life since the early 1980s."

ACT-UP founder Larry Kramer was predictably anti-PrEP at the outset, seeing it as something that sapped gay men's moral fibre and strength. Veteran HIV activist Sean Strub worried that PrEP was an avoidance of "giving [HIV-negative people] the life skills teaching them how to be healthy about their sexuality."

In response, Murphy quotes Walter Armstrong, former editor of POZ, the magazine Strub founded: "There's something really ugly about how some older gay men who've lived through AIDS say to younger guys, 'After all we've been through, I can't believe you would take PrEP and risk your life for sex.'"

He ends with the experience of one gay New Yorker, Leo Herrera, whose path to PrEP involved negotiating exactly these dilemmas. He thought, if he ever went on PrEP at all, it would be to indulge in unbridled promiscuity. Instead, he finally went on it because he fell in love with his HIV-positive partner, Michael Beard: "I thought previously I'd go on PrEP for every slut in New York City, then I found myself thinking of going on it for just one guy. I felt like I was being pulled into a big public-health trend. Was it really the best thing for me?"

Murphy relates: "I ask Herrera how he felt about being on PrEP after what he called 'the temper tantrum in my head' he'd experienced before starting the treatment—one in which it seemed like the various debates of the last half-century of gay sexuality were colliding, in miniature, as he made this one decision.

⁹ Murphy T. '*Sex Without Fear*'. New York Magazine, 13 July 2014.

“It feels like the future, like a new chapter,’ he says. Then Herrera surprises us by starting to cry. After all, a powerful history of desire and dread intertwined is not easily undone. ‘I feel very proud because a lot of men have died for me to be able to do this,’ he says.

“Beard takes Herrera’s hand. ‘Leo thinks out loud,’ he says. And then, to me, ‘Why should we continue punishing ourselves?’”

“ PrEP may indeed deliver freedom from a profound source of anxiety, it’s not taken on a whim...”

Why quote at length from a six-year-old magazine article written as PrEP was just starting to take off in the US? Partly because it documents that, for many, taking PrEP is experienced as a relief and as freedom from anxiety – but that for many, the relief is achieved only after a struggle with societal and internal norms and prohibitions about immorality, continence and self-control. Those norms and prohibitions are partly inherited from the ‘AIDS and condom-only’ era but also ones that every gay man has to struggle with when growing up in order to feel good about their sex lives in any case.

This shows that, while PrEP may indeed deliver freedom from a profound source of anxiety, it’s not taken on a whim and is still often started after a very considered process of decision.

Early qualitative research

Soon, social scientists started to validate the anecdotal findings of pieces such as Murphy’s. Research on this issue has almost exclusively been done with cisgender gay and bisexual men, although a handful of studies with other populations are reviewed at the end of this briefing.

One of the earliest was a piece of qualitative research from Seattle, conducted in 2014 and published in 2016¹⁰, that found that taking PrEP had a profound impact on gay men’s sexual health and wellbeing that went beyond PrEP’s primary function of preventing HIV infection.

“By lowering HIV risk and offering an alternative form of protection for men who have sex with men with low or inconsistent condom use, PrEP helped participants assuage feelings of anxiety and shame surrounding their sexuality, and facilitated greater sexual satisfaction, intimacy, and self-efficacy,” researcher Dr Shane Collins said.

Half the respondents had been using PrEP for three months or less at the time of the interview. A desire for lower-risk, condomless sex was the predominant driver of PrEP use. Most had sought out PrEP because they had a history of inconsistent condom use (or no condom use) and recognised that this pattern was unlikely to change, regardless of their intentions, as this man explained:

“It’s the best choice for the behaviour that I know is my behaviour ... While I’m not always safe, I certainly always want to stay HIV-negative.”

¹⁰ Collins SP et al. *The Impact of HIV Pre-exposure Prophylaxis (PrEP) Use on the Sexual Health of Men Who Have Sex with Men: A Qualitative Study in Seattle*, WA. *International Journal of Sexual Health*, 29: 55-68, 2017. See aidsmap.com/news/report-here.

Some men described selectively using condoms based on their perceptions of partners, while other men saw being exposed to other sexually transmitted infections as an acceptable risk.

“There are times when I think to myself, ‘Well, even though I’m on PrEP, maybe I shouldn’t have unprotected sex because I might catch something else.’ But there’s another part of me that says, ‘Well, those aren’t so terminal. If I got those, I could easily just get them cleared.’”

Men described the anxiety they had felt about sex before using PrEP and the stress this placed on their mental and emotional wellbeing.

“ Many men described how using PrEP helped them improve their sense of self-efficacy.”

“I had done the best that I could and I still just felt like there was no winning, like every day was a constant battle against this invisible thing that lives in our blood and kills us. And it wasn’t just when I got tested. It wasn’t just when I had sex. It was six days after I had sex.”

Some men had become fatalistic about the likelihood of acquiring HIV. The man quoted in the previous paragraph continued:

“Like, it was just gonna have to happen because the alternative is not to be intimate with anybody.”

In contrast, as the man who had had the most experience of PrEP (19 months) said, *“Being able to live without that stress and fear was very liberating.”*

Many men described how using PrEP helped them improve their sense of self-efficacy. One said, *“There are very few situations where I find myself feeling like a victim anymore.”*

The lessening of shame and anxiety led to more satisfying sexual encounters. One said: *“Now on Truvada there’s at least the opportunity for me to quiet some of that really fearful conversation that’s going on through my head, and feel more connected and good about what I’m doing.”*

For many, PrEP allowed them to enjoy being the receptive partner.

“That’s something that I never thought I would do and I never thought I could do without fear... Because I’m on PrEP, allowing myself to bottom became an option.”

Others talked about how they could now imagine themselves having relationships with HIV-positive men or talked about how PrEP had improved sexual satisfaction by providing peace of mind and allowing the couple to stop using condoms.

“[My partner] felt obligated to protect me...while there still is a possibility, that fear is gone. And it has improved our intimacy, and had a positive influence on our relationship together.”

But alongside these positive effects, the interviewees also experienced or worried about being stigmatised for their use of PrEP.

“Talking online with other people that are cruising online websites and you tell them you’re on PrEP, there was somewhat of that shaming, ‘Oh, you’re on PrEP, you must be making really bad choices to think you need to be on this.’”

In some cases this stigma was internalised, with some expressions of shame, regret and internal conflict in relation to their sexual behaviour while on PrEP. Stigma was also experienced in healthcare settings. Doctors' insistence that condoms should be used together with PrEP was often felt to be impractical and led some men to misrepresent their condom use to their doctor.

The profound impact of reducing shame and anxiety surrounding sex highlights the psychological burden of living with an elevated risk of contracting HIV, the researchers commented.

“ ...reducing shame and anxiety surrounding sex highlights the psychological burden of living with an elevated risk of contracting HIV, ”

Similar themes are picked up in a separate qualitative study¹¹ of PrEP users in the iPrEx OLE study¹², published by Dr Kimberley Koester and colleagues. In this, the first open-label extension of a large PrEP study, half of the participants, regardless of whether they had originally been in the PrEP or placebo arm of the original randomised controlled study, had depression scores over the threshold for clinically significant depression. This indicates a generalised state of poor emotional health among this study population and a need for its relief, although depression as such was not related to adherence to PrEP¹³.

Some concerns about PrEP have involved the idea of 'risk compensation'. This is the idea that if the risk of a behaviour (and therefore anxiety about it) is alleviated, people will simply take more risks, so the benefit of the alleviation is cancelled out. One example from the past is the idea that if safety features like seatbelts were introduced into cars, people would only compensate with riskier driving. (In fact, seatbelts *did* save lives.)

Willingness to have sex with PrEP users

There are two major complementary components of the anxiety about sex that PrEP may help to dissolve.

One is anxiety about HIV infection and transmission that, as has already been noted, may be a major incentive for people to use PrEP in the context of an ongoing relationship.

The other is emotional anxiety about rejection. Although this is a part of sex for everyone, from the boldest to the shyest, members of sexual and gender minorities grow up used to the idea that the vast majority of people they desire will not reciprocate, and may reject them to the point of violence or public shaming.

In the case of gay men, HIV only intensified expectations of rejection. An interesting aspect of PrEP, which we already see the early adopters quoted above grappling with, is: is my PrEP use (if disclosed or discovered) going to make me more, or less, liable to being rejected by prospective partners?

¹¹ Koester K et al. *Risk, safety and sex among male PrEP users: time for a new understanding*. *Culture, Health & Sexuality*, 19: 1301-1313, April 2017. See aidsmap.com/news/report-here.

¹² Grant RM et al. *An observational study of preexposure prophylaxis uptake, sexual practices, and HIV incidence among men and transgender women who have sex with men*. *The Lancet Infectious Diseases*, 14: 820-829, July 2014. See aidsmap.com/news/report-here.

¹³ Defechereux PA et al. *Depression and Oral FTC/TDF Pre-exposure Prophylaxis (PrEP) Among Men and Transgender Women Who Have Sex With Men (MSM/TGW)*. *AIDS and Behavior*, 20: 1478-88, July 2016.

Because of this, surveys of changing attitudes towards PrEP users by other gay men are as important as surveys of gay men's attitudes towards their own actual or contemplated PrEP use.

An Australian paper published in 2018¹⁴ found that use of PrEP and willingness to consider using PrEP increased between 2011 and 2017 among gay and bisexual men, while concerns about using it decreased. The 2015 and 2017 surveys also asked about attitudes to other men using PrEP.

Firstly, did non-PrEP users support gay and bisexual men who were taking PrEP? Just over half (52%) said they were supportive, a proportion that remained unchanged in the 2017 survey.

Secondly, would they be willing to have sex with a man on PrEP? In 2015 35% said yes. In the 2017 survey, this had increased to 49%.

Approximately three-quarters (74%) of men on PrEP provided answers suggesting they had reduced fear of HIV and more sexual pleasure because of PrEP.

However, in contrast, just 23% of non-users had reduced anxiety of HIV because of other men's use of PrEP – showing that PrEP had not abolished the fear of HIV. This supports the idea that 'early adopters' of a new technology tend to be open to change, risk-taking and attracted to new ideas and practices. Those who subsequently use it tend to be less adventurous and risk-taking, deliberating for longer before adopting an innovation. "The next wave of PrEP users in Australia may be less adventurous and require greater reassurance about PrEP's efficacy and legitimacy," the authors commented.

Quantitative studies of mental health and PrEP

Until 2019 there was little quantitative evidence that PrEP was linked to better mental health. Thereafter, evidence began to accumulate, though the actual changes documented derive from data collected several years earlier.

In mid-2019, a survey carried out by the UK PrEP advocacy organisations [PrEPster](#) and [IWantPrEPNow](#), in collaboration with Public Health England, interviewed people about how they were accessing PrEP, and how it had affected their HIV testing behaviour and choice of sexual partners¹⁵. It also asked survey participants to comment on how PrEP had affected their quality of life and psychological outlook.

Most PrEP users had a positive view of taking PrEP and three-quarters said it had had an entirely positive effect, with no downside, while another 12% reported mixed positive and negative effects.

The most commonly mentioned experience, in line with findings from other surveys, was reduced anxiety around sex: "*Greater freedom during sex, reduced anxiety, greater feeling of intimacy with partners,*" said one respondent.

¹⁴ Holt M et al. *Trends in Attitudes to and the Use of HIV Pre-exposure Prophylaxis by Australian Gay and Bisexual Men, 2011–2017: Implications for Further Implementation from a Diffusion of Innovations Perspective*. *AIDS and Behavior*, 23: 1939-1950, 2019. See [aidsmap.com news report here](#).

¹⁵ O'Halloran C et al. *Current experiences of accessing and using HIV pre-exposure prophylaxis (PrEP) in the United Kingdom: a cross-sectional online survey*, May to July 2019. *Eurosurveillance*, 24: 1900693, November 2019. See [aidsmap.com news report here](#).

Others also reported that the reduced anxiety translated into more positive sexual health choices and a greater sense of agency: *“Reduced anxiety around going to my regular screenings. In the past I would put off going for months because I was worried what the result might be despite being quite safe in my sex life,”* said one.

“ Others also reported that the reduced anxiety translated into more positive sexual health choices and a greater sense of agency”

Another said: *“I’ve actually been more cautious and aware of my sexual activity and it’s made me make more informed choices.”*

In November 2019, an [Australian study](#) found a statistically significant reduction in HIV anxiety among men who were eligible for PrEP and who were using it, from data collected in 2018¹⁶.

The data come from 1547 respondents, including 686 PrEP users, to Flux, a national, online, prospective cohort study that was established in 2015. Men were presented with three statements

about HIV anxiety:

- > “After having sex I sometimes get concerned that I might have done something risky”: 23% of men agreed or strongly agreed with this statement.
- > “I sometimes worry about HIV before having sex”: 27% agreed or strongly agreed.
- > “When I’m having sex HIV tends to come to mind”: 11% agreed or strongly agreed with this.

For each statement, men rated their degree of agreement on a six-point scale so someone who ‘strongly disagreed’ with all three questions would score 3 and someone with maximal anxiety would score 18. Adding the three scores together, the average was 8.9.

Men in a regular relationship had lower anxiety (average 8.0) than men not in a relationship (9.5). Men who reported receptive anal sex without a condom with a casual partner had higher anxiety (9.3) than men who did not (8.7).

In the cohort as a whole, HIV anxiety did *not* differ according to PrEP use. However, there was a clear difference among the men eligible to use PrEP according to Australian guidelines. Within this group, PrEP users had quite significantly lower anxiety scores (8.5) than non-PrEP users (10.4). After adjustment for other factors that could affect the results, the difference was smaller, but remained statistically significant, with an 8% reduction in anxiety scores among PrEP users compared with non-users.

¹⁶ Keen P et al. *Use of HIV Pre-exposure Prophylaxis (PrEP) Associated With Lower HIV Anxiety Among Gay and Bisexual Men in Australia Who Are at High Risk of HIV Infection: Results From the Flux Study*, Journal of Acquired Immune Deficiency Syndromes, 83: 119-125, February 2020. See [aidsmap.com news report here](https://aidsmap.com/news-report-here).

Sexual anxiety decreases in gay men after they start PrEP

The previous study was cross-sectional: it was a ‘snapshot’ of mental health indicators in a group of gay men at a single time point. This may indicate a link between PrEP use and better state of mind, but it can’t suggest causation. Gay men might be less anxious because they took PrEP; but equally, gay men who are calmer might have more self-efficacy and so be more likely to take PrEP.

Longitudinal studies, which measure anxiety levels in the same gay men before and after they start PrEP, provide better proof of causation. One was published in February 2019 by Thomas Whitfield of Hunter College in New York¹⁷.

This took data from the same group of gay men at three time points in 2016, 2017 and 2018. The men were enrolled in a longitudinal cohort study called ‘One Thousand Strong’ and were selected from a sample of HIV-negative gay and bisexual men in the US, designed to be representative in terms of area of residence, urban or rural habitat, socioeconomic status, and age. It is also more or less representative of ethnicity, except that, because a higher proportion of African Americans are HIV positive, they were somewhat under-represented in the cohort.

At three different time points participants were asked if they were currently taking PrEP, used to take it, or had never taken it. They were also asked to complete a questionnaire rating their sexual fulfilment, sexual self-esteem, and sexual anxiety on a scale of 1-4.

Typical questions might be “I am satisfied with the status of my own sexual fulfilment”, “I am pleased with how I handle my own sexual tendencies and behaviours”, and “Thinking about the sexual aspects of my life leaves me with an uneasy feeling”.

Of the 1071 men who were recruited for ‘One Thousand Strong’, 137 (12.8%) started PrEP in the study’s two years. PrEP users were predominantly White and well-educated, and nearly half had a long-term partner.

Sexual self-esteem and fulfilment did not change after starting PrEP. In baseline measures, there was a trend towards sexual self-esteem being lower in men with bisexual, as opposed to gay, identity, and men with partners were more sexually satisfied than men who were single, but PrEP made no significant difference to these scores.

But when it came to sexual anxiety, a lower score was found after men had started PrEP – and was the only factor significantly associated with less anxiety. The average score out of a maximum possible four points for all questions on sexual anxiety, taken together, was 1.46 before men started PrEP. That score went down by 0.27 points after men started PrEP. This was statistically significant ($p = 0.025$, meaning only one chance in 40 it could be a purely random finding).

“ Sexual self-esteem and fulfilment did not change after starting PrEP”

¹⁷ Whitfield T et al. *The Impact of Pre-Exposure Prophylaxis (PrEP) Use on Sexual Anxiety, Satisfaction, and Esteem Among Gay and Bisexual Men* Journal of Sex Research, 6: 1128-1135, February 2019.

Co-author Dr Jonathan Rendina told the *Contagion* news website¹⁸: “A lot of focus has been put on HIV risk criteria for starting PrEP, which I think makes sense, but these findings also suggest that simply being worried about HIV risk may be reason enough to put a patient on PrEP... We know PrEP is safe, it’ll reduce any risk should it eventually arise, and it might be what they need to reduce their worries about sex regardless of whether they are objectively at risk.”

A recent longitudinal study from Amsterdam provided more insight into on the positive mental health changes attendant on starting PrEP¹⁹. This was a longitudinal analysis of 339 gay and bisexual men and two trans women participating in the AmPrEP demonstration study in Amsterdam between 2015 and 2018.

“ A recent study from Amsterdam... strengthens the idea that anxiety about HIV infection is strongly linked to not being, or feeling, in control of one’s sexual behaviour”

Symptoms of depression and anxiety did not decline over the 2-3 years participants were in the study, although anxiety specifically about acquiring HIV considerably reduced. There was also a large reduction in a psychological issue other studies had not tried to measure quantitatively – sexual compulsivity, the feeling that you cannot control your sexual feelings or urges and that your sexual behaviour is harmful. Over the time people were in AmPrEP, the proportion who reported a high degree of sexual compulsivity on a [validated scale](#) reduced significantly from 23% to 10%.

The proportion reporting problematic use of recreational drugs (as measured by the DUDIT scale) was not as large (from 38% to 31%) but still statistically significant. Although the proportion reporting problematic drinking did not decline, the amount participants drank did.

Participants scoring significantly for anxiety at baseline were over twice as likely as other participants to develop problematic drug use, and were 70% less likely to resolve problems of sexual compulsivity. This strengthens the idea that anxiety about HIV infection is strongly linked to not being, or feeling, in control of one’s sexual behaviour.

The researchers emphasise that their study does not show that PrEP caused the improvements in mental health and addiction indicators: AmPrEP also included a counselling session at every three-monthly visit and this, and the general experience of being part of a study, may have been what helped.

As the mental health surveys use the users’ own subjective self-assessment, it’s also possible that, especially in the case of sexual compulsivity, it was people’s feelings about their behaviour, rather than the behaviour itself, that may have changed.

¹⁸ Lorenz J. ‘PrEP May Offer Psychological Benefits, Study Suggests’. *Contagion Live*, 1 April 2019.

¹⁹ Achterbergh RCA et al. *Changes in mental health and drug use among men who have sex with men using daily and event-driven pre-exposure prophylaxis: Results from a prospective demonstration project in Amsterdam, the Netherlands*. *Lancet EClinical Medicine*, 18 August 2020. See [aidsmap.com news report here](https://www.aidsmap.com/news-report-here).

Breaking the link between condomless sex and anxiety

A US online survey published in February 2020 has teased out the effects of PrEP in greater detail, though in fact it had collected data in 2016 ²⁰. It included HIV-positive, HIV-negative and status-unknown men, and included HIV-negative men who took PrEP and ones who did not. It measured three dimensions of mental health: depression, anxiety and internalised homophobia.

The survey, conducted by Dr Robert Moeller and colleagues from Middlebury College in Vermont, recruited participants via a single gay dating site.

The researchers asked participants to complete three different validated questionnaires to measure depression, anxiety and internalised homophobia (self-stigma). The [PHQ-9](#) and [GAD-7](#) questionnaires measure depression and anxiety respectively by asking respondents how many times in the last week they have experienced symptoms indicating either condition. The [IHP questionnaire](#) for internalised homophobia asks people to what extent they agree with statements such as “I often feel it best to avoid personal or social involvement with other gay/bisexual men” and “I have tried to become more sexually attracted to women”.

The researchers divided the 2406 men who answered the survey into four categories: HIV-negative PrEP users, comprising 11% of respondents; HIV-negative men who did not use PrEP (66%); HIV-positive men (11%); and men who did not know their HIV status (12%). Many of the PrEP users were dating or married, but were non-monogamous and tended to have more sexual partners than other HIV-negative men. This may support the theory that one motivator behind using PrEP instead of condoms is to improve ‘relationship discrepancy’, as PrEP is experienced as a facilitator of intimacy, rather than a barrier of it.

There was a dichotomy in the number of casual condomless sex partners in the last three months between, on the one hand, PrEP users and HIV-positive men (average number respectively 5.5 and 5.2 partners) and, on the other hand, men who did not know their status and HIV-negative men not on PrEP (respectively 1.9 and 1.6 partners).

Arguably the most striking finding of this survey is that PrEP users had the best mental health of all the respondents, by all three conditions measured (depression, anxiety and self-stigma).

Conversely, men who did not know their HIV status had the worst mental health, by all three measures. HIV-negative men not using PrEP and HIV-positive men had average, and similar, levels of mental health.

In the PHQ-9 depression scale, scores over 5, 10, 15 and 20 are rated as mild, moderate, severe and very severe respectively. In this survey, PrEP users scored 5.7, HIV-negative non-PrEP users 7.0, HIV-positive respondents 7.0 (all mildly depressed), and people who did not know their status 9.7, bringing them close to the ‘moderately depressed’ threshold.

²⁰ Moeller RW et al. *Use of PrEP, sexual behaviors and mental health correlates in a sample of gay, bisexual and other men who have sex with men*. Journal of Gay & Lesbian Mental Health, 24: 94-111, January 2020. See [aidsmap.com news report here](https://aidsmap.com/news-report-here).

For the GAD-7 anxiety scale, scores of over 5, 10 and 15 are classed as mild, moderate and severe anxiety. In this survey PrEP users scored 4.5, meaning they had no significant anxiety. HIV-negative non-PrEP users and HIV-positive respondents scored 5.4 and 5.5 respectively, and men who did not know their status 7.3, meaning they had mild anxiety.

For the internalised homophobia scale, the minimum and maximum scores were 9 and 45. PrEP takers had the lowest average score at 15.1; HIV-positive men, interestingly, had the second-lowest scores at 16.4; HIV-negative non-PrEP users' scores averaged 18.1; and men who did not know their status 20.6.

The researchers wanted to see if PrEP use changed an association seen in this and other studies between higher rates of depression and anxiety and more condomless sex. This turned out to be the case for anxiety, but was not significantly so for depression.

“ The most striking finding of this survey is that PrEP users had the best mental health of all the respondents.”

There was certainly an association between more condomless sex and higher rates of depression and anxiety in all non-PrEP users. The average depression score in non-PrEP users who had no condomless casual sex partners in the last three months was 6.8 (out of a maximum 27), while it was 8.2 in those with 20 or more partners. With anxiety, the difference was even larger, with those reporting no condomless sex scoring 5.25 (out of a maximum 21) and those reporting 20 or more partners scoring 7.0.

(Note that this association can't attribute causality to this link; men might be depressed or anxious because they were worried about unprotected sex and the associated HIV risk; equally, they could be having more unprotected sex as a coping behaviour for depression or anxiety.)

This association was far less marked for depression in PrEP users, with the depression score only increasing from 6.4 to 6.6 as the number of condomless casual sex partners changed from zero to 20. However, once the fourth factor – self-stigma – was fed into the analysis the link between PrEP use and lack of depression about condomless sex was no longer significant.

With anxiety, however, the link remained. PrEP users scored consistently below 5 on the anxiety scale regardless of how many condomless sexual partners they had had, and this remained unchanged by self-stigma.

The difference in mental health scores between PrEP users and others, though consistent, were not especially large. The researchers note that a five-point decrease on the PHQ-9 and GAD-7 scales is regarded as a clinically significant improvement; this study found a four-point difference in depression between PrEP users and men who did not know their HIV status and a 2.8-point difference in anxiety.

Across a population, however, it may be important: for instance, the difference between men and women in such scales, despite mental ill-health being a strongly gendered condition, is generally in the region of one point.

The researchers emphasise the finding on anxiety: “While having a higher number of condomless-anal-intercourse partners is associated with increased anxiety among participants who are not on PrEP, whether HIV positive or HIV-negative, the use of PrEP seems to moderate this difference.”

They note that a number of other studies have found that depression, anxiety and internalised homophobia are all associated with greater HIV risk via condomless sex in gay men.

“These mental health burdens are frequently co-occurring and often function synergistically, as a syndemic,” they note, “[yet] our results indicate *lower* levels of mental health burden among PrEP users are related to significantly *higher* rates of condomless anal intercourse.”

The researchers speculate that, although there might be other factors such as PrEP users having better access to mental health care, this is most likely because PrEP users (correctly, in the case of HIV) do not experience condomless anal intercourse as risky and that the link to anxiety about it is therefore broken.

Sex without fear, revisited

Meanwhile, in the UK in 2017, another person who decided to start PrEP was Matt Cain, at the time Editor-in-Chief of the gay magazine *Attitude* and erstwhile culture editor for Channel Four.

At that time, he wrote in *The Guardian*, PrEP was controversial even among his own magazine’s readers²¹.

“‘Why should my taxes pay for these sluts to have bareback sex?’ is a typical comment. But I was worried that my reaction was the result of anti-gay conditioning, being brought up to think that I didn’t deserve the same rights as the rest of society, and I wanted to challenge this by taking the drug for three months to find out more.

“I start telling people what I am doing. With the occasional exception, they express disapproval or, at the very least, unease. Several grimace at the news and a few friends tell me they ‘struggle with’ PrEP. At a party, I discuss the subject with a gay man I have known for seven years and feel encouraged when he is supportive. When I ask if he himself is taking PrEP he erupts in anger and asks how I dare suggest such a thing.”

Cain suggested that some of these attitudes to PrEP takers are due to deep-rooted shame in a lot of gay men, not about being ‘sluts’, but about what ‘sluts’ really stands for – being a bottom, the receptive partner in gay sex.

“There are a whole host of reasons why the passive partner may find persuading his partner [to use a condom] difficult – such as low self-esteem, thinking he doesn’t deserve him, or will lose him. PrEP frees passive gay men from this tricky and often risky negotiation and offers them the chance to empower and protect themselves.”

Cain feels anxious about his first experience of condomless sex after starting PrEP but “telling myself I am protected, I go through with it.”

²¹ Cain, Matt. ‘Sex without fear – my experiment with the HIV-prevention drug PrEP’. *The Guardian*, 22 June 2017.

“Afterwards, I burst into tears. I feel dirty and guilty, as if I have let myself down. I grew up in the 1980s, when fear of HIV/Aids was at its highest and I had it drilled into me that I always had to wear a condom.”

But, almost in a spirit of enquiry, he continues. One of his partners “tells me he isn’t put off by the fact that I am taking PrEP but he would prefer to use a condom.” Not to do so “would feel as if we were rushing into the intimate stages of a trusting relationship to have condom-less sex straightaway.”

Eventually, however, he has several experiences “without regret or guilt” and meets others who have benefitted from PrEP.

“A friend who started taking PrEP at the same time as me...says he associated sex so closely with the threat of death and disease that he became neurotic and was unable to open himself up to a relationship. But since taking PrEP he has been able to use sex to connect with someone on a more intimate level – and he and the first man he had condom-less sex with are now in a relationship.”

In the course of a trip to the US, he finds (by now, just three years on from Tim Murphy’s identically named article) a culture more advanced in its attitudes towards PrEP – and notes how this has removed a lot of the expectations gay men have towards HIV disclosure.

“During the course of my trip I have sex with a few men and condoms are not even mentioned – nor is HIV status discussed. It is clear that PrEP has changed things. In the past, I had always been struck by how upfront Americans were about their HIV status – and asking about mine. It seems this is no longer an issue or even a conversation – and the sexual activity I experience is entirely free from fear. The drug is completely normalised and there is no stigma.

“In the same way that the contraceptive pill freed so many women from associations between sex and the scandal of an unwanted pregnancy, PrEP can free gay men from linking sex and death. It allows us to have sex how it should be experienced – innocently and joyously. It is perfectly natural and a desire that has always been part of me. I had been robbed of it for more than two decades.”

Cain’s comment in 2017 that PrEP was “normalised” among the gay men he met may not apply to all parts of the gay scene, but it does seem to be becoming a reality in areas and communities where PrEP is widely available. In the most recent of the Australian national gay men’s surveys²², whose data was taken from 2017-2018, PrEP had not only overtaken condoms as the prevention method of choice among HIV-negative gay men, but was now the method used by the majority.

In that survey 50% of those surveyed were using PrEP as their primary prevention method and 37% were using condoms regularly. This left about one in eight gay men (13%) who were never, or infrequently, using either prevention strategy – and this proportion, representing men who used no reliable HIV prevention method, has in fact shrunk in recent years. If the testimonies in the studies and articles above are to be believed, then this represents not merely a decline in the proportion of men vulnerable to HIV, but also the proportion who worry about it.

22 Broady TR et al. *Australian Gay and Bisexual Men Who Use Condoms, PrEP or Rarely Practise HIV Risk Reduction with Casual Sex Partners: An Analysis of National, Behavioural Surveillance Data, 2017-2018*. AIDS and Behavior, published ahead of print, May 2020. See aidsmap.com/news/report-here.

PrEP and mental health in other populations

All the studies and articles previously mentioned relate to cisgender gay and bisexual men. For other populations, we do not yet have clear quantitative evidence that PrEP is associated with better mental health.

Trans men and women

In the case of trans women and men, who are clearly, as studies show, at high risk of HIV, the risk factors for it are often assumed to be similar to those for gay and bisexual cis men, but they have different and additional risk factors to the ones they share with cis men.²³

It is already widely known that HIV prevalence is even higher in trans women than in gay men. In a global review of studies of trans people, HIV prevalence in trans women ranged from 3.6 to 45% in non-US studies and 2 to 40% in US ones.

Trans men are far less well studied. There have only been six studies in the US and five elsewhere that have even reported on HIV prevalence in trans men and transmasculine persons as a separate group, with HIV prevalence ranging from zero to 8%. (Most of these studies were small, and in the study that found the highest prevalence, this was actually two people.)

However, there are data to show that trans men may be at significant risk of HIV and poor mental health, and that these issues may be related.

One study, from Massachusetts in the US, was a community-based convenience sample that included 173 transmasculine people who have sex with cis men among 452 trans, non-binary or otherwise non-gender-conforming individuals²⁴. It found an association between the number of negative psychosocial conditions (alcohol and substance use, depression, anxiety, childhood abuse, and intimate partner violence) and increased odds of sexual risk.

The handful of studies which have reported on PrEP usage in trans men have found that usage was low.”^{25,26,27}

With trans women, the issue is not so much that this is an under-studied population as it is one where the presence of trans women in studies has in the past been under-reported, with trans women recorded as men who have sex with men. One reason for the invisibility of trans women as a group, even in studies that in fact have included them, is to do with their extreme experience of stigmatisation.

23 Poteat T et al. *Global Epidemiology of HIV Infection and Related Syndemics Affecting Transgender People*. Journal of Acquired Immune Deficiency Syndromes, 72 Suppl 3: S210-S219, August 2016. See [aidsmap.com news report here](https://aidsmap.com/news-report-here).

24 Reisner SL et al. *Syndemics and gender affirmation: HIV sexual risk in female-to-male trans masculine adults reporting sexual contact with cisgender males*. International Journal of STD & AIDS, 27: 955–966, October 2016.

25 Sevelius, JM et al. *HIV Testing and PrEP Use in a National Probability Sample of Sexually Active Transgender People in the United States*. Journal of Acquired Immune Deficiency Syndromes, 84: 437–442, August 2020. See [aidsmap.com news report here](https://aidsmap.com/news-report-here).

26 Golub SA et al. *High Rates of PrEP Eligibility but Low Rates of PrEP Access Among a National Sample of Transmasculine Individuals*. Journal of Acquired Immune Deficiency Syndromes, 82: e1-e7, September 2019. See [aidsmap.com news report here](https://aidsmap.com/news-report-here).

27 Reisner SL et al. *High risk and low uptake of pre-exposure prophylaxis to prevent HIV acquisition in a national online sample of transgender men who have sex with men in the United States*. Journal of the International AIDS Society, 22: e25391, September 2019. See [aidsmap.com news report here](https://aidsmap.com/news-report-here).

Stigmatisation and violence are major contributors to poor mental health in trans women and to the ‘syndemic’ of issues that can greatly magnify their risk. In one theoretical review ²⁸ of trans women’s vulnerability to HIV, the writers put it this way:

“We hypothesise that both structural violence (e.g., transphobia, sexism, racism) and direct violence (e.g., physical, sexual, and emotional abuse) can threaten identity... Identity threat can result in negative affective states (e.g., guilt, shame, and anxiety), which are aversive for psychological wellbeing. The individual will in turn attempt to cope—either adaptively or maladaptively. Possible maladaptive strategies include condomless sex, substance misuse, and disengagement from care... Adaptive coping strategies include the derivation of social support and engagement with care.”

These strategies – both maladaptive and adaptive – were illustrated in an interesting study ²⁹ that interviewed 19 Black and Latina transgender women who were taking PrEP in 2019, and found that PrEP users had more adaptive coping strategies.

“ Stigmatisation and violence are major contributors to poor mental health in trans women”

Their average age was 28, 68% defined as heterosexual, and most were, on average, poor (63% had an annual income of less than \$10,000.) They had been on PrEP for between two weeks and nearly four years (6.2 months on average). Sixty per cent said they used condoms as well as PrEP for receptive anal sex and 74% said their PrEP adherence was good.

The participants recounted an overwhelming set of stereotypes and assumptions directed to them. People believed that “all transgender women will get HIV, that they already have HIV, and that they are to blame for the continued spread of HIV.”

They recounted an almost daily experience of “public verbal attacks, death wishes, judgement and rejection” and were cautious about disclosing their PrEP use, because this tended to confirm people’s negative image both of them and of PrEP. One said that when friends heard she was taking Truvada, they automatically assumed she had HIV.

Despite this, 60% had talked about their PrEP use to trusted others – and they had found that the experience, when they had control over disclosure, was mainly positive. One had found that PrEP did reduce the anxiety of sexual encounters, largely because it reduced partners’ anxiety: “[My sex partners] are a little more relieved. I don’t know if it’s because they know you have to be negative to be on it, but they’re more like, ‘Okay that makes me feel better to know that you don’t have it.’” (Latina, age 21, 44 months on PrEP).

Others encountered supportive reactions from their close friends and family:

“[My friends] were happy...for me. I’ve always been warned, ‘Don’t trust anybody.’ Now that I’m on PrEP, they’re happy for my health status, that I won’t catch the virus if a condom breaks or just taking that risk.” (Latina, age 50, 1 month on PrEP).

²⁸ Jaspal R et al. *Human Immunodeficiency Virus and Trans Women: A Literature Review*. Transgender Health, 3: 239-250, December 2018.

²⁹ Brooks RA et al. *Experiences of Pre-Exposure Prophylaxis Stigma, Social Support, and Information Dissemination Among Black and Latina Transgender Women Who Are Using Pre-Exposure Prophylaxis*. Transgender Health, 4: 188-196, August 2019.

"It was a good thing; [my parents] recommended it [PrEP]. They think it's the best for me because a girl like me should always be safe with my sex life as well, regardless of who I'm having sex with." (Black, age 28, 0.5 months on PrEP).

The participants were generally enthusiastic enough about PrEP to recommended it to other friends in the trans community and to sexual partners:

"I think that it's very important to share this information with all people of colour—well, not just people of colour, but with everybody. A lot of my girls are into the sex work. They make more money without the condom than with the condoms...If you're going to be out there making your money, at least make it in a way that you can sleep good at night and know that you have some form of protection in your body against these people that you know nothing about." (Black, age 48, 6 months on PrEP).

"I do let [partners] know, 'Look, I don't have HIV and I'm on PrEP. What do you want to do?' And I even ask if they know about it. Like, I get to have a nice conversation about why it's important. Even him, as a straight man, should be on PrEP." (Black, age 48, 2.5 months on PrEP).

Cisgender heterosexual men and women

When it comes to the far larger population of cis women and heterosexual men, widespread PrEP rollout is only just starting to happen in enough volume for studies of its social and psychological effects to be completed and published.

In addition, study of the psychological effects of PrEP has to be filtered through the fact that, while there are plenty of studies showing that *having* HIV is associated with poor mental health in cis women and heterosexual men, drug users and trans people, there is less evidence that fear of acquiring HIV is as specifically tied to the risk of sexual transmission as it appears to be in gay and bisexual men, and possibly in trans people.

For HIV-negative members of these populations, while there are many social pressures and double standards to deal with about sexual behaviour and about drug use, they are not channelled through the risk of HIV as much as they are for gay and bisexual men and trans people. They are not so defined as 'the people who get HIV'. A woman may have more anxiety about pregnancy, gender-based violence or the welfare of her children than HIV; a heterosexual man may worry more about status, career, and masculinity; a drug user about supply and police oppression. The wider community they are surrounded by may also see HIV as less of a priority for them, whatever the degree of risk for individuals.

Thus the fear and stigma of HIV may not be so focused on specific sexual practices; it may operate more on the level of 'spoiled identity', as stigma has been called. People who have already chosen to adopt, or who felt they had no choice but to adopt, a gay or trans identity have already had experience overcoming internal prohibitions against what 'type' of people they should be. This fear of a spoiled identity may be a much stronger issue for members of the cis heterosexual majority population, even in high-prevalence countries.

HIV stigma is certainly powerful in higher-prevalence countries. Just to pick one survey, researchers interviewed 500 HIV-negative Black South Africans in Cape Town for a study published in 2000³⁰. They asked people if they agreed with the following statements, among others:

“Most people with HIV get it from being weak and foolish” (22% agreed).

“You can’t trust people like that” (24% agreed).

“They should feel guilty for what they’ve done, really” (36% agreed).

Having negative opinions about people with HIV correlated strongly with fear of HIV infection and of testing.

Fifteen years later, therefore, it is a contrast to find young African heterosexuals – admittedly in a different part of Africa – commenting on PrEP and how it might improve their lives.

“ Fifteen years later... it is a contrast to find young African heterosexuals... commenting on PrEP and how it might improve their lives.”

Dr Carol Camlin from the University of California, San Francisco conducted the qualitative study after PrEP became available through the Sustainable East Africa Research in Community Health (SEARCH) study in Kenya and Uganda ³¹. As part of door-to-door community testing campaigns, PrEP was offered free of charge to individuals who had tested HIV negative and were at elevated risk of HIV.

Data were collected through focus group discussions and in-depth interviews with a total of 111 men and women under the age of 35, including both PrEP users and non-users.

For many young people, the worst days of the AIDS epidemic were something that they had heard about but not personally experienced. Many HIV-positive people in these communities were on antiretroviral treatment. Ironically because the perceived severity of infection with HIV was somewhat diminished, it deterred some young people from seeking PrEP.

Concerns about contracting HIV, and the resultant desire to use PrEP, were patterned along gender lines with young males and females expressing different fears and motivations. This was linked to the different degrees of agency that young men and women had. While PrEP was seen as attractive for men because it was viewed as liberating and a means of enacting masculinity, women viewed it as an additional form of protection that could offer more control over sexual encounters.

PrEP was also intimately linked to HIV-related stigma, with some participants (mostly men) fearing that others would think that they had HIV if they took PrEP. For some, the idea of taking daily medication was at odds with being young and healthy.

Interviews with people who had started PrEP found that they were still cautious about letting partners know, for fear of being accused of unfaithfulness. One said:

“You will not tell him that you are using PrEP because he will not agree to it: ‘why are you taking PrEP and yet I am the one you consider your boyfriend?’” – Kenyan female.

³⁰ Kalichman S and Simbayi L. *HIV testing attitudes, AIDS stigma, and voluntary HIV counselling and testing in a black township in Cape Town, South Africa*. Sexually Transmitted Infections, 79: 442-447, December 2003. See aidsmap.com/news/report/here.

³¹ Camlin CS et al. *Understanding Demand for PrEP and Early Experiences of PrEP Use Among Young Adults in Rural Kenya and Uganda: A Qualitative Study*. AIDS and Behavior, 24: 2149-2162, January 2020. See aidsmap.com/news/report/here.

However, the most commonly expressed feeling, as with the studies already cited from gay and bisexual men, was one of comfort and relief from anxiety:

"I feel really comfortable knowing that chances of HIV risk are minimal." – Kenyan male.

"I thought of it as something that will protect my life. I first got a shock – 'Really? There is a drug that prevents HIV?' ...I was very happy about it because my husband can't stick to one woman, yet I don't want to get infected." – Ugandan female.

"The risk I have is that if get infected with HIV, I will fail to fulfill my dreams. Because you may have a desire to do something, like to care for yourself or your family... I want to complete my studies when I am ok. Secondly, I want to have a family that is admired by people." – Ugandan male.

We are in the early days of how PrEP may change attitudes and opinions towards sex and HIV in non-gay and non-trans populations. The researchers emphasised that PrEP wouldn't change traditionally gendered attitudes:

"Perceptions of HIV risk were highly gendered: young men in our study... perceived their risks of HIV to mostly stem from their own behaviours, and therefore under their more direct control." Some young men however were aware of their female partners also having relationships with "older men whose financial status is somehow stable" who might have HIV.

The researchers continued: "Young women, who had little control over partner behaviours and felt pressure to engage in transactional and condomless sex, viewed PrEP as a means to assert control over sexual risks."

"...for women...the attraction of PrEP is linked to the degree to which it may increase their sense of agency over their lives."

Confirmation that, for women in particular, the attraction of PrEP is linked to the degree to which it may increase their sense of agency over their lives – *and* the distrust of PrEP is, conversely, linked to their experience of lack of agency, is borne out by one of the very few qualitative studies of PrEP among women who inject drugs ever to have been done, in Philadelphia in the US last year ³².

The researchers commented that the study participants "viewed HIV as severe, perceived themselves to be susceptible to HIV, and believed PrEP was beneficial for HIV prevention. For some, however, real and perceived barriers outweighed benefits. Barriers included HIV stigma, fear of side effects, and needing assurance that PrEP care will be available long-term. Despite viewing PrEP as an important HIV prevention tool, not all women who inject drugs who were offered PrEP initiated it."

Despite the fact that not all participants opted to start PrEP, all participants recognised that PrEP is a beneficial prevention tool for anyone at risk for HIV.

"In actuality, if you only have to take a pill once a day to protect yourself, and not getting the [HIV] virus, it's a miracle..."

³² Felsher M et al. *An Exploration of Pre-exposure Prophylaxis (PrEP) Initiation Among Women Who Inject Drugs..* Archives of Sexual Behavior, 49: 2205-2212, April 2020 *See [aidsmap.com news report here](https://aidsmap.com/news-report-here).*

For the women who opted to accept PrEP, the main benefit reported was that it is a tool that is within their control and does not require any co-operation from sex partners. This was especially relevant in the context of sex work.

"[PrEP] is awesome...in prostitution, jerks take the condoms off. You tell them to use a condom and they don't...So we can protect ourselves with PrEP."

PrEP has been available in the US since 2012, and Chicago is one of the US cities where there is a high prevalence and incidence of HIV among women of colour. Despite this, and despite the fact that there has been a high-profile PrEP campaign there, PrEP4Love, which includes images of and is directed towards women, a recent study showed continuing low awareness and usage of PrEP among a group of primarily Black women recruited at a hospital emergency department and an STI clinic³³.

Only 30% of the 370 women in the survey had heard of PrEP, and only 3% knew someone who took it. This lack of knowledge was not due to lack of interest. Women selected for qualitative interviews in a focus group expressed surprise and anger that they had not been informed about PrEP, even though most were regular users of healthcare services.

The survey revealed that the healthcare workers who women trusted were, in the main, primary care physicians with whom they had built a trusting relationship, and not sexual health or family planning specialists. They also felt that the local PrEP campaign felt as if it was directed towards gay men. Several felt that usage of PrEP would only become common among their community if there was a strong body of peer advocates recruited who would spread the word to other African-American women.

"...a recent study... confirmed that young women preferred messages that were empowering and motivational,"

One focus group consisted of women who were taking PrEP. Although most had started PrEP in response to a possible HIV exposure, they had stayed on it because it gave them a sense of empowerment. One woman said she took it because she could protect herself independent of others' actions: *"PrEP is for protecting me, everyone else needs to protect themselves, and I don't need to be part of it."*

Another interesting finding is that they did not want to keep their PrEP use secret, and that the self-efficacy achieved through disclosure was seen as an important part of the experience.

Back in South Africa, a recent study of a project to develop demand-creation materials for PrEP directed to young people confirmed that young women preferred messages that were empowering and motivational, rather than focusing on risk, prevention or even health³⁴. The primary communication challenge was to convince healthy young women with low motivation to take a daily pill to prevent HIV, a condition that the young women did not consistently feel to be at risk from.

³³ Hirschhorn LR et al. *Black cisgender women's PrEP knowledge, attitudes, preferences and experiences in Chicago*. Journal of Acquired Immune Deficiency Syndromes, 84: 497-507, August 2020. See [aidsmap.com news report here](https://aidsmap.com/news-report-here).

³⁴ Morton JF et al. *Evaluation of a behavior-centered design strategy for creating demand for oral PrEP among young women in Cape Town, South Africa*. Gates Open Research, 4: 29, March 2020. See [aidsmap.com news report here](https://aidsmap.com/news-report-here).

The researchers found that demand creation could harness young women's desire to increase their attractiveness to partners, increase emotional intimacy, avoid the social consequences of having HIV, and become a role model by being an early adopter of PrEP. Nine women aged 16-19 who had previously taken PrEP endorsed two themes in particular:

- > PrEP enhances the power you have. ("You call the shots, make your own decisions, are independent and don't have to rely on your partner to prevent HIV").
- > Take care of yourself: PrEP increases your self-worth. ("Taking the pill gives you the opportunity to be part of an 'exclusive group' that is turning the tide against HIV").

The video that was produced ([You can watch it here](#)) emphasised young people's control over their lives and being part of a generation that will end HIV. Evaluation of the video showed that interest was greatest among women who currently had a primary partner, especially if the relationship had been formed in the last six months.

This brings us right back to the studies we quoted at the start of this briefing – that one of the most important perceived advantages of PrEP, and one of the ways to increase demand for it, is not so much to emphasise that it eliminates a negative (infection with HIV) as to emphasise that it can accentuate a positive (improve the intimacy and durability of relationships).