

When reality does not live up to expectations: Anticipating when to stop PrEP

By Dr Dean Murphy, Research Fellow, Kirby Institute, UNSW, Sydney and Alfred Health, Melbourne.

A recently published paper from San Francisco on recent HIV-diagnoses among users of PrEP (pre-exposure prophylaxis) found that almost all but one of the seroconverters had actually stopped taking the pills (1). Reasons for stopping included issues related to drug consumption, housing, cost and insurance, attending medical appointments, perceiving risk, and entering a new relationship.

For *AIDS2020* we reviewed qualitative data (based on a total of 101 in-depth interviews with 59 participants conducted between 2014 and 2018) from Australia to see what people said about stopping PrEP (2).

Participants were asked to anticipate reasons why they might stop taking PrEP in the future, and also to describe any experiences of taking a break from, or discontinuing, PrEP.

By far the most common reason participants gave for imagining that they might discontinue PrEP in the future was entering a new relationship. The ways in which these future relationships were described usually focused on 'monogamy' or 'love', with less explicit emphasis on HIV risk. When participants speculated about the steps involved in stopping PrEP in the context of entering a future relationship, they anticipated lengthy discussions – occurring only after trust had been established – which some described as happening over a period of 6 or 12 months.

In contrast, among participants who had *actually* discontinued PrEP due to entering a relationship, decisions about discontinuing were often very sudden, even when undertaken with clinical support. Also, some participants who had stayed on PrEP after starting a new relationship reported that they didn't initially tell their new partner they were on PrEP.

Other reasons that participants imagined stopping PrEP were related to side effects, drug interactions and/or toxicity. Interestingly, participants who discontinued PrEP – or took a break – were likely to do so without discussing it with their clinician (even if it was related to side effects and concerns about other adverse events). Although this finding is similar to other, more recent, research (1), we found this somewhat surprising, given that all our study participants were taking part in PrEP clinical studies.

Other considerations of stopping PrEP were framed in terms of imagined futures – that were often quite remote from the present day. These futures included descriptions of decreased sexual activity due to: ageing; decreased sexual interest; and/or decreased sexual desirability. They also included imagined *collective* futures, for example where a cure for HIV had been discovered.

While clinical guidance documents for prescribers (3, 4) necessarily focus on HIV risk, and adherence to the dosing requirements, they do not address other contextual factors that are more pertinent to PrEP users.

References

1. Spinelli MA, Laborde N, Kinley P, Whitacre R, Scott HM, Walker N, et al. Missed opportunities to prevent HIV infections among pre-exposure prophylaxis users: a population-based mixed methods study, San Francisco, United States. *Journal of the International AIDS Society*. 2020;23(4):e25472.
2. Murphy DA, Ellard J, Ryan K, Holt M, de Wit JBF, Wright J. Anticipated and actual experiences of discontinuing PrEP reflect the 'imagined futures' and everyday concerns of gay and bisexual men, rather than HIV risk: Implications for service provision and health promotion. *AIDS 2020: 23rd International AIDS Conference; July 6-10; Virtual2020*.
3. The Australasian Society of HIV Viral Hepatitis and Sexual Health Medicine. *PrEP Guidelines Update. Prevent HIV by Prescribing PrEP*. Sydney; 2019.
4. Wright E, Grulich A, Roy K, Boyd M, Cornelisse V, Russell D, et al. Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine HIV pre-exposure prophylaxis: clinical guidelines. Update April 2018. *J Virus Erad*. 2018;4(2):143-59.