

Anticipated and actual reasons for discontinuing PrEP among gay and bisexual men reflect everyday concerns in addition to perceived HIV risk: Implications for service provision and health promotion

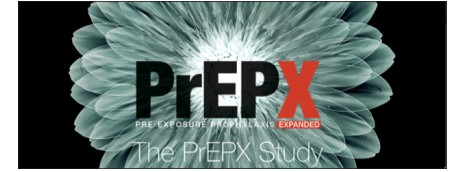
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Background

- Increasing interest in the reasons why people might discontinue PrEP after having started.
- Clinical guidance documents for prescribers recommend discussing PrEP discontinuation with patients at time of PrEP initiation.
 - Focus on HIV risk, and adherence to dosing requirements.
 - May not address other contextual factors that are more pertinent to PrEP users.



Reasons for stopping/pausing PrEP

- Having less sex (Holt et al. 2019; Hammoud et al. 2020)
- No longer at risk [or reassessment of risk] (Holt et al. 2019; Whitfield et al. 2019; Spinelli et al. 2020)
- In a [monogamous] relationship (Holt et al. 2019; Ryan et al. 2019b; Spinelli et al. 2020)
- Side effects (Zimmermann et al. 2019)
- Concerns about taking medication (Holt et al. 2019)
- Substance use, mental health and housing loss (Ryan et al. 2019a; Spinelli et al. 2020)
- Cost of PrEP, insurance coverage, cost and time of medical visits (Whitfield et al. 2019; Spinelli et al. 2020)
- Clinician referral [vis-à-vis self referral] (Ryan et al. 2019a)
- Younger age (Ryan et al. 2019a; Whitfield et al. 2019)



Methods

- Two PrEP demonstration clinical trials (the VicPrEP study [2014–2016], and the PrEPX study [2016–2018]) in Victoria, Australia.
- Face-to-face interviews (A small number of follow-up interviews conducted via telephone if participants were unable to meet face-to-face.)
- Analysis focuses on:
 - reasons participants believed they might stop taking PrEP at some point in the future
 - any actual experiences of discontinuing, or taking a break from, PrEP
- Interviews were digitally recorded and transcribed.
- NVivo12 software used to manage and code data.
- Critical Discourse Analysis (CDA) approach.



Participants

- 59 participants (plus 42 follow-up interviews approx. 18 months later)
 - 101 in-depth interviews.
- All 59 participants described themselves as gay or bisexual men, including two trans men.
- Average age
 - VicPrEP 39.7 years (median 37.5; range 25–57).
 - PrEPX 35.2 years (median 30; range 22–68).



Findings

- Most participants provided reasons about why they might discontinue PrEP at some point in the future.
- Seven participants also described why they had either discontinued PrEP altogether (or had stopped taking the pills for a period of time).
- Participants' anticipated reasons for discontinuing PrEP were usually framed in terms of their everyday concerns or 'imagined futures'
 - rather than being explicitly related to HIV risk



Relationships

- Entering a new relationship
 - potential reason for discontinuing PrEP in the future.
- Future relationships described in idealised ways
 - usually framed in terms of 'love' or 'monogamy' rather than HIV risk.
- Stopping PrEP imagined as a decision preceded by detailed discussions and occurring only after trust had been established.



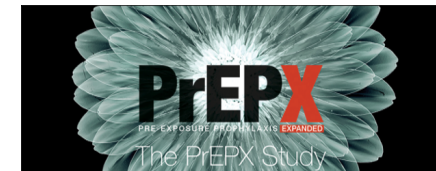
Relationships [cont.]

- Among participants who discontinued PrEP, decisions were often very sudden, even when undertaken with clinical support.

Yeah, so [my partner] and I had a chat about being monogamous [...]. And after we had that conversation I went to my doctor and said, 'Look, this is the situation. I don't think I need to be on PrEP anymore.' (Cole, age 27, PrEPX)

- Discussion with clinician was rare.
- Some participants who had remained on PrEP didn't initially tell their new partner they were on PrEP, or told their partner that they needed to stay on PrEP because of their obligation or commitment to the study.

So me being part of [the study], well, I hope it helps other people, so [that's why] I'd stay on it. And that would be my reasoning to him if he had a problem. (Vaughn, age 26, PrEPX)



Side effects, interactions, toxicity

- Concerns about side-effects and toxicities were also important as potential reasons for stopping.

The only thing that's of concern to me is the long-term ramifications of being on testosterone, you know, affecting my, what is it, kidneys or liver or whatever? So, you know, that, and long-term PrEP. We still don't know 100 per cent what that's going to be. (Oskar, age 41, trans man, PrEPX)

- Stopping/pausing because of concerns about PrEP adversely affecting other medical interventions.

I haven't discussed it with anyone in the study or anything like that, but I've had to make the decision myself to not take the medication until after the surgeries, just in case it affects it or anything like that. (Dustin, age 29, PrEPX)



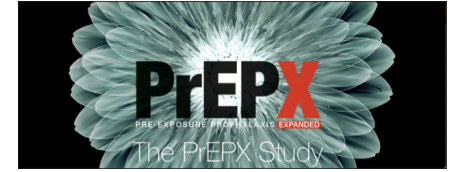
Side effects, interactions, toxicity [cont.]

- Concerns about the long-term effects of PrEP (highlighted in particular by younger men)
 - related to body image, beliefs about pharmaceuticals in general, or about HIV antiretrovirals specifically.

Yeah, it's a chemical in my body. I think about that a lot. (Millard, age 25, PrEPX)

This is quite vain but [I wonder about] what it does to your body, physically. I think I find a lot of people that are on treatment seem to age pretty quickly. (Roman, age 28, VicPrEP).

- Concerns sometimes related to specific aspects of their life such as intention to be a sperm donor, or participation in sports that carry increased risk of fractures.



‘Control’

- For a minority of participants, PrEP represented a sense of control that extended beyond HIV prevention.
- These participants anticipated being able to stop PrEP only when their circumstances changed.
 - specific issues related to anxiety or mental health.
 - concern about drug consumption, particularly in chemsex scenes.
- Stopping PrEP was therefore something associated with a future where they were no longer engaging in drug use.
- In the meantime PrEP was highly valued as a way of preventing HIV.

‘Imagined futures’

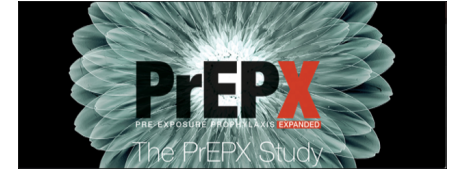
- Considerations of discontinuing PrEP also framed in terms of ‘imagined futures’
 - decreased sexual activity due to: ageing; decreased sexual interest or decreased sexual desirability.

...if my libido dropped dramatically. (Diego, age 38, PrEPX)

I feel like I want to keep taking it while I have some, you know, marketability. (Clayton, age 51, VicPrEP)

- Some participants also referred to imagined collective futures
 - a vaccine or cure for HIV – or even a different prophylactic approach – which would therefore make PrEP redundant.

...unless HIV infection just stopped altogether and there was a cure. (Isaias, age 25, PrEPX)



Discussion

- Focus on *anticipated* reasons for discontinuation, as well as actual *experiences* of people who had actually ceased PrEP, either temporarily or permanently.
- Future discontinuation of PrEP was anticipated in context of starting a new relationship
 - Echoes approaches to negotiating other HIV prevention strategies (e.g. condoms) with relationship partners – although focus on monogamy.
 - Differences between the imagined scenarios and the accounts of people who had discontinued PrEP.
- Participants who discontinued PrEP 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).
- Participants were accessing PrEP through short/medium-term projects, and ongoing supply of the drug was not guaranteed initially at the study end.
 - This fact may have foreclosed thinking about other reasons for stopping.
 - However, the prospect of losing access to PrEP *may* also have provoked other speculative thinking about PrEP.



Conclusion

- Although HIV risk is an important consideration, this risk is viewed through the lens of everyday life.
- Discontinuing/pausing PrEP does not always follow imagined scenarios.
- Useful insights for service provision and health promotion interventions.
 - Reframing PrEP in ways that correspond to the concerns of users is vital in supporting patients to anticipate discontinuation, and also to prevent unintentional breaks...and to support re-initiation of PrEP where appropriate.
- Recent policy changes (shift from 'eligibility' to 'suitability')
 - May enable new modes of engagement



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