# From training wheels to chemical condoms: exploring the narratives of PrEP discontinuation

This paper explores experiences of PrEP, a HIV-prevention intervention, among bugchasers, gay men who eroticise HIV. While PrEP has been hailed as a 'game changer' in HIV-prevention, little attention has been paid to why and how some people may discontinue it in the face of HIV risk, such as bugchasers do. This paper relies on interview data with bugchasers themselves to discuss the process of discontinuation and its effects. The paper argues that, for these men, discontinuation is a fluid, complex and sometimes contradictory process. It also describes how participants perceived themselves as being at different stages of discontinuation. The paper also analysed how these men saw PrEP as a barrier to intimacy, risk and a tool to negotiate their desires and identity: through discontinuing PrEP, these men were able to reflect on and build their identities as bugchasers.

Keywords: PrEP, HIV, sexual health, discontinuation, adherence.

PrEP, the acronym for pre-exposure prophylaxis refers to the use of antiretroviral medication to prevent HIV infection in those at risk of it. Since the US Food and Drug Administration (FDA) approved it in 2012, PrEP has been hailed as a 'game changer' in HIV prevention and has become a 'hot topic' in debates around sexuality (Brady 2015; Rhoden-Paul 2019). While PrEP is available for a range of people, these debates have mostly crystallized around gay men's use of it. PrEP, which has become the latest element in the toolbox of HIV prevention, is believed to have played a significant role in the 29% decrease in new infections among gay and bisexual men in London in 2016 (Brown, et al. 2017). However, the promise of PrEP has continually been dampened by poor availability, relatively low uptake among key at-risk populations and poor adherence. As PrEP becomes more available to more people worldwide, it is important to understand that it "is a dynamic phenomenon that is more than just a pharmacologic intervention—that is, getting PrEP 'to work' is more complicated than simply 'getting drugs into bodies" (Auerbach and Hoppe 2015, n.p.). Research is needed about how people make sense of PrEP and what interventions around PrEP use are effective. In particular, it is necessary—and currently under studied—to explore why and how some people stop taking PrEP while they engage in practices that put them at enhanced risk of HIV.

This paper develops this area of research by exploring some men's experiences of discontinuing PrEP and how this process may contribute to negotiating and building their desires and (sexual) identity. To do so, I analyze three interviews with 'bugchasers', gay men who eroticize HIV<sup>i</sup>. While bugchasers eroticize the virus, they are also ambivalent about their desire for actual infection. These three men, Scott, Milo and Luke<sup>ii</sup>, understand PrEP differently and evidence different stages and experiences of discontinuation: for Scott, PrEP is a barrier to intimacy akin to 'chemical condoms', for Milo, PrEP and its discontinuation are a way of experimenting with his desires ('training wheels') and, for Luke, a tool to define his own identity. While this is a niche sample, these men's experiences provide an illustrative vignette of how PrEP discontinuation can support people's negotiation of their desires and identities within a practice so far ignored by PrEP research.

First, this paper provides a summary of PrEP. In particular, I review current research about users' meanings for PrEP, barriers to uptake and challenges to adherence. Then, I move to considering the importance and complexity that underlies PrEP discontinuation. Second, this paper overviews the figure of the bugchaser and the reasons why these men eroticize HIV and risk-taking. Third, I discuss the methodology. Fourth, the stories of Scott, Milo and Luke are analyzed: Scott has discontinued PrEP and sees it as a barrier to intimacy, Milo experiments with stopping PrEP as a way of negotiating his desires, and Luke uses PrEP to negotiate his bugchaser identity. Finally, I consider the limitations of these findings and further explore how PrEP discontinuation is fluid, complex, and related to desires and identity.

#### What is PrEP?

PrEP is an HIV-prevention strategy that uses antiretroviral drugs (also used in the treatment of HIV infection) to protect HIV negative people from infection (Peabody and Nutland 2018). PrEP does not prevent any sexually transmitted infection (STI) other than HIV, and so it is frequently combined with other risk-reduction techniques (such as condoms, regular STI testing, etc.). It consists of a single-pill<sup>iii</sup> that may be taken daily or around particular high-risk sexual encounters ('on demand' dosing). PrEP may be used for shorter or longer periods during which there is an enhanced risk of HIV, these go from days to years. A large number of trials have proven that PrEP is highly efficacious<sup>iv</sup> in preventing HIV but only if taken as prescribed (Fonner, et al. 2016; Molina, et al. 2015; McCormack, et al. 2016). The availability of PrEP is inconsistent across the world, although the three men considered here all had similar access to it (see methodology).

PrEP is not solely a biomedical device, but also part of a larger chain of medical and technological interventions in sexual health, including condoms, PEP, TasP, and undetectability (Auerbach and Hoppe 2015, n.p.). As part of this chain, PrEP has mobilized pre-exiting cultural debates about sexuality and has generated a groundswell in the gay community. Dean (2015) goes as far as to suggest that "condom free sex is mediated by Truvada even when the participants are not on it, because the drug has crystallized as a mediating idea about what worry-free sex between men in the 21st century might be" (229). In a similar tone, Feliciantonio (2017) suggests that PrEP may be a tool for "new collective political possibilities" centered around the re-appropriation of sex outside the medical models of HIV transmission for gay men.

PrEP has generated debates around promiscuity and condomless sex. Discourses of 'slut shaming' that had been previously attached to other prophylactics have resurfaced with PrEP, particularly around the image of the 'Truvada Whore', representing gay men whose use of PrEP is said to correspond to promiscuity and irresponsibility (Myers and Sepkowitz 2013; Spieldenner 2016). The public debates that took place around the views of PrEP and the need for its provision have been termed by Belluz as 'Truvada Wars' (Belluz 2014). These wars have also been portrayed in the media: Jaspal and Nerlich (2017) argue that mainstream media constructed a rigid binary between describing PrEP as a 'revolutionary tool' and as a 'risky biomedical intervention' with high uncertainty and likely to be used as a lifestyle drug. Other analyses suggest that newspaper reports on PrEP in the UK developed two narratives: one about citizen responsibility and one about the public-health need for the drug, that changed and shifted over time (Young, et al. 2020).

Research has found PrEP to be effective not only in preventing HIV but also in alleviating anxieties and fears about the potential risk of HIV infection which, in turn, enhances interpersonal and sexual relationships (Gamarel and Golub 2015; Jaspal and Daramilas 2016). In line with this, Brooks et al. (2011) found that people were motivated to take PrEP because they saw it as ameliorating their fears about HIV. However, despite these positive results and its high effectivity, uptake of PrEP has been low among key at-risk populations, groups that remain at higher risk for HIV because of a number of factors (including the status of partners, prevalence of HIV in their communities, etc.). Research suggests that key barriers for uptake are: concerns about being stigmatized as reckless or promiscuous, concerns about side effects, cost, lack of awareness about PrEP and its effectivity, and a lack of access to expert sources of information or expert medical professionals (Brooks, et al. 2011; Grant, et al. 2014; Marcus, et al. 2016; Jaspal and Daramilas 2016; Hammack, et al. 2019). Other barriers such as access to healthcare more generally, able-bodiedness, etc. also play significant roles in these exclusion processes.

#### PrEP adherence and discontinuation

As mentioned above, PrEP has been found to be highly efficacious in preventing HIV if taken appropriately (Haberer, et al. 2015). In fact, the 'real world' effectiveness of PrEP relies on adherence. For example, the large-scale iPrEx trial—which measured the effect of PrEP among men who have sex with men and transgender women—saw a 92% reduction in the relative risk of HIV infection in participants who adhered to PrEP, but less than half that in those who did not (Grant, et al. 2010). Poor adherence across trials has been inconsistently linked to young age, use of intravenous drugs, and personal preference (Glidden, et al. 2016; Ryan, et al. 2019a). In the case of PrEP, however, adherence "is complex and must be understood within the context of variable risk for HIV infection and the use of other HIV prevention methods" (Haberer, et al. 2015, n.p.).

Unlike medication for HIV, which is taken at for the rest of a person's life after diagnosis, PrEP is only advised during 'seasons of risk', periods of heightened HIV risk. Thus, PrEP may be taken only around particular sexual encounters ('on demand' or 'intermittent') or may be taken daily for a period of time (weeks, months, or years). While this possibility is useful because sexual risk is not permanent but "fluctuates between periods of high and low HIV risk [due to] various personal and psychological factors" (Carlo Hojilla, et al. 2016, 6) the fact that people may take it every day or intermittently makes it difficult to determine what adherence and discontinuation are. Haberer et al. (2015) suggest the idea of 'prevention-effective' adherence: full daily adherence may not be necessary or desirable, since HIV risk is not permanent and other prevention tools may be used (such as condoms). At the same time, discontinuation has been measured in a number of ways, such as disengagement from services or not seeking drug refills for over 210 days (Ryan, et al. 2019b). This paper uses the term 'discontinuation' to refer to participant's active choice to stop taking PrEP (as opposed to reducing the number of doses) temporary or permanently.

As PrEP users move in and out of 'seasons of risk', they want to adapt their PrEP use to these and seek "guidance on how to start and stop PrEP" (Koester, et al. 2014, 7). However, most available clinical guidelines emphasize the significance of starting

PrEP—as a process requiring blood screenings, counselling, and HIV and STI screenings—but omit such detailed information about discontinuing it. For example, the World Health Organisation Implementation Tools for PrEP (World Health Organisation 2017a; World Health Organisation 2017b) offer a multitude of templates and guides for clinicians advising patients on starting PrEP, but their only comment on discontinuation is that patients should wait 28 days after their last potential exposure to HIV. Similarly, the guidelines for PrEP by the British HIV Association only discuss discontinuation as an option for patients no longer at risk or who are not adherent (Brady, et al. 2019). While these documents only focus on the possibility of discontinuing PrEP when no longer at risk, large-scale trials have determined that a significant number of participants may discontinue PrEP while remaining at risk of HIV. I will consider two examples here. Grant et al. discuss the iPrEx trial:

Sustained engagement is a significant challenge for PrEP services. [...] Disengagement from PrEP services was substantial and infection rates during gaps in PrEP use were high. Among those who stopped PrEP, disengagement typically occurred early after a brief period of experimentation with PrEP. (Grant, et al. 2014, 8)

This suggest three things: first, that discontinuation is a major issue for PrEP delivery. Second, that significant numbers of participants who discontinued did so *while* at risk for HIV, as the high rates of infection during the 'gaps' evidence. And, third, that discontinuation is not necessarily permanent, but that PrEP users may choose to 'take breaks' off PrEP. This is further detailed by Ryan et al. (2019b) in their discussion of the PrEPX study, a large population level demonstration study for PrEP that took place in Victoria, Australia, between 2016 and 2018. The team found that 25% of the participants discontinued PrEP. Of these, 22% recommenced it at a later point but 78% did not. Interestingly, the research also found that participants' rate of STIs other than HIV was similar before and after discontinuation, meaning that participants who discontinued PrEP did not necessarily change their sexual practices to account for the lack of protection from HIV afforded by PrEP once they stop taking it.

All this research suggests that a significant number of people who discontinue PrEP do so while still at risk of HIV, a situation not considered by existing guidelines. At the same time, there is little information about the processes of discontinuation and how PrEP users may negotiate these. This article explores the case of bugchasing to explore these complexities around PrEP use. Bugchasing is an effective inroad into these debates because bugchasers are men who *eroticise* HIV and thus may provide particularly clear examples of how discontinuing PrEP (while remaining aware of their risk of contracting HIV) may help to negotiate desires and build identities.

### What is bugchasing?

This article is part of a larger project examining the experiences of bugchasers, their use of PrEP and of the internet. Bugchasers are gay men who eroticise HIV. Far from a fixed identity position, this label stands for a complex variety of affects, experiences, and practices: some men actually seek HIV and engage in a multitude of high-risk sexual encounters to be infected, whereas others fantasize about infection but also wish to remain HIV negative, for example by using PrEP. While bugchasing is eminently a gay practice (see footnote 1), it is varied in age and exists in countries around the global

north. Bugchasing is statistically rare and taboo, and bugchasers have found ample spaces in the internet where to meet partners, exchange information and pornography, or obtain community support. There is a lack of ethnographic detail on bugchasing, with just a handful of quality work on it, such as Dean's *Unlimited Intimacy* (2009) and Gauthier and Forsyth (1999). To date, this is the second piece of research examining bugchasers' views and use of PrEP (see Garcia-Iglesias 2020c).

Before exploring bugchasers' perceptions of PrEP, it is worth considering some of the reasons for the eroticising of HIV. Given the variety of experiences and demographics encompassed by bugchasing, no single factor can be said to 'cause' bugchasing. Rather, these are potential contextual elements to bugchasing. Some researchers argue that bugchasing and barebacking—the different but connected eroticising of condomless anal intercourse among gay men—are a response to the imposition of condoms and the ever-present fear of HIV (Crossley 2004; Crossley 2002). Thus, bugchasers would be aiming to foreclose the anxieties generated by the uncertainty of potential infection to "get on with the business of living out their lives in a more uninhibited fashion" (Gauthier and Forsyth 1999, 93). Bugchasing may also be a response to feelings of loneliness on the part of HIV negative people as their friends and lovers contracted HIV. In this way, HIV would be seen as a way of accessing a community of HIV positive individuals, a sort of viral brotherhood (Dean 2009). In fact, the idea of 'viral intimacy' and membership will be key to understanding Scott's story below.

Particularly interesting for this paper are the discussions of bugchasing and risk-taking. Gauthier and Forsyth suggest that bugchasers may perceive themselves as "holy fighters" of 'gayness' (95), with HIV being a sort of battle wound (Dean 2009, 52) in a quest for the ultimate gay identity (Morris and Paasonen 2014). This argument is picked up by Grov (2006), who suggest that bugchasing may be perceived as a form of arousing risk-seeking in a risk-averse society. Dawson et al. (2005) go further to suggest that it is the act of seeking HIV itself (regardless of whether the virus is contracted or not) that is arousing, a line also endorsed by Dean (2009) when he argues that it is bugchasers' lack of fear of infection that endows them with hypermasculinity (as a response to society's feminization of anal sexuality).

What is key to thinking about bugchasing and PrEP is that the eroticising of HIV and its prevention are not mutually exclusive. Bugchasing is varied: some men enjoy the fantasy with little intention of carrying it out in 'real life', others seek to be infected by any means. Most frequently, men move fluidly in between these extremes, sometimes being aroused by the thought of it, sometimes seeking to prevent it for fear of the long-term complications of infection (Garcia-Iglesias 2020a). PrEP appears as an effective tool for men to negotiate these fluid movements because, unlike the condom, it is invisible and, thus, allows men to engage in the 'fantasy' of bugchasing while having sex with others if they so wish.

## Methodology

This paper focuses on three participant stories: Scott, Milo and Luke. These three stories were selected out of the twenty-two that compose an ethnographic exploration of bugchasing online and offline (Garcia-Iglesias 2020d). While twelve participants had experiences of PrEP, the three stories considered here were selected because they represent different affects towards PrEP and different stages of PrEP discontinuation,

while also being particularly illustrative of the processes of meaning making and desire negotiation that underpin PrEP use. These three participants were in Australia, UK and France: while availability across countries and regions is inconsistent, all three participants all had access to PrEP at no cost through government-subsidized programmes that also included routine testing for HIV and STIs. In these particular three cases, neither access nor retention into care posed challenges to participants. All participants were recruited through a research Twitter account and labelled themselves as 'bugchasers' in one way or another. Participants were given Information Sheets and Consent forms in line with university guidelines.

Give the rarity of bugchasing, geographic dispersal of participants, and intimate nature of the topics, interviews were conducted via Skype. Interviews were in-depth and lightly structured with a series of themes to cover but open to participants' interests. The use of Skype interviewing has been found by previous researchers to provide flexibility, preserve rapport, and given participants the opportunity to choose different levels of exposure, as well as preserve their intimacy (Deakin and Wakefield 2013; Hanna 2012; Seitz 2015). In this particular case, the availability of mobile data allowed participants to find comfortable and private venues to conduct the interview (such as their cars) and negotiate whether they wanted to reveal their face or not. This method has been used effectively by Huysamen (2018) to research equally intimate issues.

Given the taboo and intimate nature of the topic discussed, previous reviewers have raised concerns about the possibility that participants may misrepresent their experiences. It is true that there is no clear way to verify participants' testimonies, but it is equally true that this is a characteristic common to most qualitative research, particularly that dealing with intimate issues. After all, interviews are dramatic encounters (Lune and Berg 2017) and research encounters are not free from the social performativity of everyday life (Goffman 1959). While it is possible that some excerpts present a degree of exaggeration or misrepresentation, these should not be taken as skewing the results but rather as evidencing the degree to which bugchasing is as much about fantasy as it is about reality. The stories presented here explore how three men perceive PrEP as a barrier to intimacy, a method to negotiate desires and identity, and how they experiment with discontinuation.

#### Scott: PrEP as a chemical condom

Scott is a 53-year-old man from Australia. He is committed to bugchasing and spends a significant part of his day looking for partners and visiting sex-clubs to have sex with multiple men. He explains: "I've come full spectrum, I think. Safe sex to experiencing how amazing HIV is, how much better feeling it is." He argues that he started strictly using condoms but, around 2010, he commenced to have condomless anal sex. From there, he became more interested in bugchasing. He now refuses condoms and spends a significant part of his life searching for a partner to infect him. In the past two years, he has been more actively seeking infection but has been unlucky so far, which he attributes to the low prevalence of untreated HIV in his area. PrEP has played, for Scott, a significant part in the process of coming to terms with his own desires. In an email before the interview, Scott had explained that he had been on PrEP after having it offered by his doctor. Scott acknowledges that PrEP "is good for people who want to remain negative," but he had decided to stop it two years before the interview. This came up in the interview:

Interviewer: Can you elaborate a bit more about why you stopped PrEP? Scott: It's just that I felt it was blocking what I was accepting from

someone else. It was a chemical condom. I was taking guys in my body, even the ones I couldn't see in dark rooms. I needed to

make a decision, and stopped PrEP.

Scott describes PrEP as a 'chemical condom'. This is significant because it evidences how PrEP does not arrive to an empty field of signification, but rather links to pre-existing narratives about condoms. While PrEP is not a condom in the sense that it does not prevent other STIs or pregnancy, Scott resorts to the image of the condom to articulate his perception of PrEP as a barrier to intimacy. He is not necessarily referring to physical intimacy (precluded for some by the latex barrier of the condom), but to a sort of fantasy viral intimacy based on the exchange of bodily fluids and, Scott hopes, HIV. The role of intimacy has been explored by scholars before, who suggest that the transmission of HIV for bugchasers serves to establish profound links akin to a life-long marriage as well as belonging to a larger community (Dean 2009). The notion of PrEP-as-chemical-condom is not unique to Scott. Preciado writes:

The birth control pill and Truvada share the same mode of operation: they are chemical condoms designed to prevent "risks" during sexual intercourse, regardless of whether this risk is an unintended pregnancy or the transmission of HIV. (Preciado 2015, n.p.)<sup>vi</sup>

Preciado, while not discussing bugchasing, evidences the degree to which PrEP ties in with pre-existing narratives and may be perceived as a barrier to 'risk'. It is this foreclosing of risk that Scott finds a 'turn off'. Finally, it is also worth realising that Scott conceptualises his discontinuation of PrEP as an active choice ("I needed to make a decision"). Far from a passive withdrawal or failure to adhere (or be retained into care), Scott takes an individual decision to stop PrEP in order to increase his perceived risk. This risk-taking decision serves him to further his feelings of intimacy and connection with other men, as well as build his own identity as a 'bugchaser'.

### Milo: stopping PrEP and coming to terms with desires

Milo is a twenty-eight-year-old man from France. Milo is located in a liminal zone: he spends significant amounts of time on bugchasing websites and talking about bugchasing on social media, routinely engages in condomless anal intercourse, and actively seeks HIV positive partners but, at the same time, he does not confidently label himself as a bugchaser. The complexity of his situation is evidenced by his use of PrEP, which he discusses at two moments in the interview:

I'm actually on PrEP, but not all the time. I think it's a great way to stay HIV negative as you can still bareback. As many bugchasers say, it's like 'training wheels' for the moment you decide to go without it.

And later acknowledges his discontinuation,

It's been a few months since I really stopped taking my PrEP pills regularly. During August, I totally stopped it for 1 month and got loaded by four guys

(thee anon and one friend). It was a real turn-on not knowing what would happen.

At the beginning of this paper, it was explained how difficult it was to determine what discontinuation was in the case of PrEP—which does not need to be taken daily. Milo evidences this complication with his acknowledgement that he is on PrEP but, at the same time, that he has not taken it for the past month—despite engaging in seemingly risk behaviors. This juxtaposition reveals how Milo is experimenting with his PrEP use as a way of negotiating his desires and identity as a bugchaser.

Milo mobilizes the image of PrEP as 'training wheels', which is common among bugchasers: the potential of PrEP to separate sexuality from HIV risk is what makes Milo realize just how aroused he was at the potential of risk itself. Thus, PrEP allows Milo to come to terms with his own desire for 'risk' in his sexuality—he is coming to understand that it is HIV risk that arouses him. In doing so, PrEP acts as 'training wheels' not only because it allows Milo to gain confidence on his desires but because, in doing so, it facilitates the building of an identity as a 'bugchaser' who commits to those desires for HIV.

It is also worth noting that the idea of 'training wheels' may generate an unwarranted sense of linearity by which PrEP use will lead to its discontinuation and search for HIV. This narrative was also present in Scott's interview. However, both Milo and Luke—the next participant—disprove this. Milo's story is far from linear: it is a contradictory and fluid process of PrEP use and discontinuation and Milo makes it clear that he is not sure whether he will return to PrEP or not. Thus, PrEP is a tool for negotiating desires in complex and non-linear ways.

#### Luke: experimenting with discontinuation

Luke is a thirty-four-year-old man from London. Luke made clear in the interview that his bugchasing is eminently fantasy and he is taking PrEP regularly as part of a nation-wide trial. At the beginning of the interview, Luke explains that he is aroused by the 'taboo-breaking' character of bugchasing but that he has no intention of actually seeking HIV. However, complications arise during our conversation. First, Luke argues that he is increasingly more interested in the HIV status of his potential partners:

Interviewer: So you think you tend to hook-up with people based more on

their HIV status than before?

Luke: I'd definitely say so, yeah. Definitely so. It's not primary, the

main thing that I go out for when I'm looking, but it's definitely, definitely, one of the... like, in my preferential vision more often.

This points towards an increasing significance of his bugchasing desires in his sexual practices. He continues:

Interviewer: Do you think you're a bugchaser yourself?

Luke: Hmm... eh... I would say probably in the last... I would say

when I was younger, definitely, definitely not. In the last year or

so, I've come pretty close to it.

Interviewer: How do you define coming closer to it?

Luke:

Well... there's been times when, you know, I've had lots of unprotected sex with people knowing fair well what their status is but have been taking the medication [PrEP] and my status, as it currently is, is still negative. I suppose it's whether or not I ever have the inclination to then turn around and don't take the medication [...] as it were. I suppose it's still... hmm... it's still... I haven't actually gone through with it as of yet, if that makes sense.

This exchange reveals that, for Luke, 'coming closer' to being a bugchaser is equated with the possibility of discontinuing PrEP. Thus, discontinuation appears as an assertion of identity. Unlike Scott or Milo, Luke is still only theoretically thinking about the impact of potential discontinuation. He describes 'going through the motions' of bugchasing by engaging in seemingly high-risk encounters while, at the same time, remaining adherent to PrEP. Interestingly, PrEP for Luke serves to negotiate his own bugchasing desires, his position between bugchasing 'fantasy' and 'reality'. Preciado also talks about the relevance of PrEP for identity:

Furthermore, with chemical condoms, the decision to use them is no longer made during the sexual act, but in advance, so that by swallowing the molecule, the consumer builds his own subjectivity in a temporal relationship of projection into the future: it is a question of being transformed by the ingestion of the drug<sup>vii</sup>. (Preciado 2015)

Luke takes PrEP daily, in the morning, and thus daily negotiates his desires and identity. In taking PrEP, he is confronted with his behaviours and desires, and with their potential effects. This process of locating himself in relation to fantasy and reality everyday may be difficult, as evidenced by his uncertainty about whether he will "turn around" and not take PrEP at some point. Luke thus illustrates one of the most interesting features of PrEP: unlike condoms—which people have to decide about using while 'in the heat of the moment'—PrEP requires cold-headed action *before* sex is happening. PrEP forces people to think about their desires, practices and HIV risk every day. Luke evidences this and explains how PrEP may serve to negotiate his identity.

## Thinking beyond PrEP

Since its approval in 2012, PrEP has been hailed as a 'game changer' in HIV prevention (Brady 2015; Rhoden-Paul 2019), and research has shown that it has the potential to become so. However, to develop effective delivery programs, it is necessary that we understand how people make sense of it, particularly how they may perceive it negatively. The stories of Scott, Milo and Luke evidence that PrEP discontinuation can be a complex process of negotiating desires, risk and identity. Scott sees PrEP as a 'chemical condom' and barrier to intimacy, and actively discontinuing it helps him build his identity as a bugchaser. Milo thinks of PrEP as 'training wheels' that allow him to gain confidence on his desires and facilitates committing to an identity as bugchaser. Luke, finally, is perhaps the one most unsure about discontinuation and yet nonetheless he most clearly evidences how thinking about discontinuation confronts him with his desire and helps him negotiate his position in between bugchasing fantasy and reality<sup>viii</sup>. These men's stories and bugchasing desires are evidently niche and yet nonetheless exploring their narratives becomes an inroad to considering how PrEP

discontinuation (much overlooked in PrEP guidelines) can and does have complex, emotional and identarian aspects beyond passive disengagements or lack of risk.

This research has two clear limitations. The first is that these men choose to actively discontinue (or think about actively discontinue) PrEP. This is a privileged option when so many people who discontinue PrEP do so because of systemic barriers (lack of insurance, affordability, lack of specialized healthcare provision, racism, ableism, etc.) or for reasons such as side-effects or stigma. At the same time, it is also worth noting that this paper did not consider the broader questions of PrEP as an intervention: the routines of accessing healthcare, testing, use of PEP (post-exposure prophylaxis), distrust of medical establishment, etc. These were not considered in the current piece because the three participants, Scott, Milo and Luke, did not discuss these as relevant to their decisions to discontinue (or think about discontinuing).

### Building through discontinuation

This article proposes two key conclusions: first, that discontinuation is a fluid and flexible process, far from linear or strict decisions. And, second, that discontinuation—for these men—serves to experiment with desires and build an identity. The stories of Scott, Milo and Luke evidence the difficulty that lies in attempting to define discontinuation: their processes are complex, fluid and varied and go from "making a decision" to ambivalently moving between periods of taking and not taking PrEP. Their decisions are also framed within ongoing processes of negotiating their desires and practices. This is in contrast with the paucity of information about discontinuation provided in many guidelines and protocols for PrEP (see above). Thus, guidance for PrEP should consider how people make sense of it (and its discontinuation) in subjective and contextual ways.

The second and, perhaps more interesting, finding is the conceptualization of PrEP discontinuation as a process of negotiation of desires and building of a bugchasing identity. As Preciado (2015) suggests, far from simple and non-invasive, PrEP taking ties into existing narratives about medicalization, intimacy and connection. Not only so, but, since it has to be ingested before the sexual activity commences, it also brings to the fore processes of negotiating desires and identities—much more so when those desires and identities are as stigmatized as bugchasing is in Scott, Milo and Luke's contexts. Perhaps the most enticing of the findings is a sort of reversal of PrEP: while it is hailed by many because it forecloses HIV risk and in many cases the anxiety this generated, the men interviewed here describe how, in foreclosing risk, PrEP made them aware of their desires for that risk itself. That is, in the absence of risk PrEP granted, the relevance of that risk became central to their sexual lives. While this could be seen as unique to bugchasing, the prevalence of debates about risk compensation regarding PrEP hint at this dynamic being a more general concern, even if there is scant empirical data that support this theory (Jones 2017; Marcus, et al. 2013).

Besides risk or, rather, through risk and its acceptance, Scott, Milo and Luke also use PrEP discontinuation as a process through which to build their own identities as bugchasers. 'Bugchaser' is far from a fixed, stable or agreed upon label, and these three men do all identify as bugchasers to an extent despite being at very different stages of PrEP use and risk taking. Nonetheless, their replies evidence a common perception that discontinuing PrEP is part of a larger claim to a bugchasing identity. The stories of Milo

and Luke in particular reveal how this is a complex process: while they did come forward to participate in a research project that ostensibly asked for 'bugchasing participants', they also show an ambivalence about just how much of that identity they are willing to take on, how they balance their desires and risk. PrEP (and, in particular for this case, PrEP discontinuation) thus arises not only as an intervention for HIV prevention, but also a tool through which to negotiate desires and identity.

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#### References

- Auerbach, Judith D, and Trevor Hoppe. 2015. "Beyond 'Getting Drugs into Bodies': Social Science Perspectives on Pre-Exposure Prophylaxis for HIV." *Journal of the International AIDS society* 18: n.p.
- Belluz, Julia. 2014. "The Truvada Wars." The British Medical Journal 348.
- Brady, Michael. 2015. "HIV Prevention Finally Has a Game-Changer, and It's Called Truvada." *The Guardian*, February 26, <a href="https://www.theguardian.com/commentisfree/2015/feb/26/hiv-treatment-game-changer-truvada-nhs-trial">https://www.theguardian.com/commentisfree/2015/feb/26/hiv-treatment-game-changer-truvada-nhs-trial</a>.
- Brady, Michael, et al. 2019. "Bhiva/Bashh Guidelines on the Use of HIV Pre-Exposure Prophylaxis (PrEP) 2018." *HIV Medicine* 20 Suppl 2 (Mar): s2-s80. http://dx.doi.org/10.1111/hiv.12718.
- Brooks, Ronald A., et al. 2011. "Motivators, Concerns and Barriers to Adoption of Pre-Exposure Prophylaxis for HIV-Prevention among Gay and Bisexual Men in HIV-Serodiscordant Male Relationships." *AIDS Care* 23, no. 9: 1136-1145.
- Brown, Alison, et al. 2017. *Towards Elimination of HIV Transmission, AIDS and HIV-Related Deaths in the Uk 2017 Report*. London: Public Health England.
- Carlo Hojilla, J., et al. 2016. "Sexual Behavior, Risk Compensation, and HIV Prevention Strategies among Participants in the San Francisco PrEPDemonstration Project: A Qualitative Analysis of Counseling Notes." *AIDS Behavior* 20, no. 7 (Jul): 1461-9. <a href="http://dx.doi.org/10.1007/s10461-015-1055-5">http://dx.doi.org/10.1007/s10461-015-1055-5</a>.
- Crossley, Michele L. 2002. "The Perils of Health Promotion and the 'Barebacking' Backlash." *Health: An Interdisciplinary Journal for the Study of Health, Illness, and Medicine* 6, no. 1: 47-68.
- Crossley, Michele L. 2004. "Making Sense of 'Barebacking': Gay Men's Narratives, Unsafe Sex, and the 'Resistance Habitus'." *British Journal of Social Psychology* 43: 225-244.
- Dawson, Alvin G., et al. 2005. "Evidence of HIV Transmission Risk in Barebacking Men-Who-Have-Sex-with-Men: Cases from the Internet." *Journal of Gay and Lesbian Psychotherapy* 9, no. 3-4: 73-83.
- Deakin, Hannah, and Kelly Wakefield. 2013. "Skype Interviewing: Reflections of Two Phd Researchers." *Qualitative Research* 14, no. 5: 603-616. http://dx.doi.org/10.1177/1468794113488126.
- Dean, Tim. 2009. *Unlimited Intimacy: Reflections on the Subculture of Barebacking*. Chicago: University of Chicago Press.
- Dean, Tim. 2015. "Mediated Intimacies: Raw Sex, Truvada, and the Biopolitics of Chemoprophylaxis." *Sexualities* 18, no. 1-2: 224-246. http://dx.doi.org/10.1177/136360715569137.
- Feliciantonio, Cesare di. 2017. "The Political Economy of Gay Sex under Homonormativity: Bareback, PrEP and Welfare Provision." *Society+Space*. Accessed September 1, 2020. <a href="https://societyandspace.org/2017/10/31/the-political-economy-of-gay-sex-under-homonormativity-bareback-prepandwelfare-provision/">https://societyandspace.org/2017/10/31/the-political-economy-of-gay-sex-under-homonormativity-bareback-prepandwelfare-provision/</a>
- Fonner, V. A., et al. 2016. "Effectiveness and Safety of Oral HIV Preexposure Prophylaxis for All Populations." *AIDS* 30, no. 12 (Jul 31): 1973-1983. http://dx.doi.org/10.1097/QAD.00000000001145.
- Gamarel, Kristi E., and Sarit A. Golub. 2015. "Intimacy Motivators and Pre-Exposure Prophylaxis (PrEP) Adoption Intentions among HIV-Negative Men Who Have

- Sex with Men (Msm) in Romantic Relationships." *Annals of Behavioural Medicine* 49: 177-186. <a href="http://dx.doi.org/10.1007/s12160-014-9646-3">http://dx.doi.org/10.1007/s12160-014-9646-3</a>.
- García-Iglesias, Jaime. 2020a. "Wanting HIV Is 'Such a Hot Choice': Exploring Bugchasers' Fluid Identities and Online Engagements." *Deviant Behavior* 41 (10): 1232–43. https://doi.org/10.1080/01639625.2019.1606617.
- García-Iglesias, Jaime. 2020b. "Viral Breedings: HIV as Pregnancy among Bugchasers." *NORMA* 15 (3–4): 221–34. https://doi.org/10.1080/18902138.2020.1744408.
- García-Iglesias, Jaime. 2020c. "'PrEP Is like an Adult Using Floaties': Meanings and New Identities of PrEP among a Niche Sample of Gay Men." *Culture, Health & Sexuality*, October, 1–14. <a href="https://doi.org/10.1080/13691058.2020.1821096">https://doi.org/10.1080/13691058.2020.1821096</a>.
- García-Iglesias, Jaime. 2020d. "Writing Bugchasing Ethnoperformance: Creative Representations of Online Interactions." *Sexualities* Online fir. https://doi.org/10.1177/1363460719896967.
- García-Iglesias, Jaime, and Joe Strong. 2021. "From Contradictory to Complementary: Acknowledging the Complex Everyday Choices of Men's Sexualities." Medical Humanities Blog, Feburary 3. Available at: <a href="https://blogs.bmj.com/medical-humanities/2021/02/03/from-contradictory-to-complementary-acknowledging-the-complex-everyday-choices-of-mens-sexualities/">https://blogs.bmj.com/medical-humanities/2021/02/03/from-contradictory-to-complementary-acknowledging-the-complex-everyday-choices-of-mens-sexualities/</a>.
- Gauthier, Deann K., and Craig J. Forsyth. 1999. "Bareback Sex, Bug Chasers, and the Gift of Death." *Deviant Behaviour* 20, no. 1: 85-100.
- Glidden, David V, et al. 2016. "Symptoms, Side Effects and Adherence in the Iprex Open-Label Extension." *Clinical Infectious Diseases* 62, no. 9 (May 1): 1172-7. <a href="http://dx.doi.org/10.1093/cid/ciw022">http://dx.doi.org/10.1093/cid/ciw022</a>.
- Goffman, Erving. 1959. *The Presentation of Self in Everyday Life*. London: Penguin. Gonzalez, Octavio R. 2010. "Tracking the Bugchaser: Giving 'the Gift' of HIV/AIDS." *Cultural Critique* 75: 82-113.
- Gonzalez, Octavio R. 2012. "Review of Unlimited Intimacy: Reflections on the Subculture of Barebacking by Tim Dean." *Cultural Critique* 81: 125-132.
- Grant, R. M., et al. 2010. "Preexposure Chemoprophylaxis for HIV Prevention in Men Who Have Sex with Men." *New England Journal of Medicine* 363, no. 27 (Dec 30): 2587-2599. <a href="http://dx.doi.org/10.1056/NEJMoa1011205">http://dx.doi.org/10.1056/NEJMoa1011205</a>.
- Grant, Robert M., et al. 2014. "Uptake of Pre-Exposure Prophylaxis, Sexual Practices, and HIV Incidence in Men and Transgender Women Who Have Sex with Men: A Cohort Study." *The Lancet Infectious Diseases* 14, no. 9: 820-829. http://dx.doi.org/10.1016/s1473-3099(14)70847-3.
- Grov, Christian, and Jeffrey T. Parsons. 2006. "Bug Chasing and Gift Giving: The Potential for HIV Transmission among Barebackers on the Internet." *AIDS Education and Prevention* 18, no. 6: 490-503.
- Haberer, J. E., et al. 2015. "Defining Success with HIV Pre-Exposure Prophylaxis: A Prevention-Effective Adherence Paradigm." *AIDS* 29, no. 11 (Jul 17): 1277-85. http://dx.doi.org/10.1097/QAD.000000000000647.
- Hammack, Phillip L, et al. 2019. "Making Meaning of the Impact of Pre-Exposure Prophylaxis (PrEP) on Public Health and Sexual Culture: Narratives of Three Generations of Gay and Bisexual Men." *Archives of Sexual Behavior* 48, no. 4 (May): 1041-1058. <a href="http://dx.doi.org/10.1007/s10508-019-1417-6">http://dx.doi.org/10.1007/s10508-019-1417-6</a>.
- Hanna, Paul. 2012. "Using Internet Technologies (Such as Skype) as a Research Medium: A Research Note." *Qualitative Research* 12, no. 2: 239-242. http://dx.doi.org/10.1177/1468794111426607.

- Huysamen, Monique. 2018. "Reflecting on the Interview as En Erotic Encounter." *Sexualties* 0, no. 0: 1-17.
- Jaspal, Rusi, and Christos Daramilas. 2016. "Perceptions of Pre-Exposure Prophylaxis (PrEP) among HIV-Negative and HIV-Positive Men Who Have Sex with Men (Msm)." *Cogent Medicine* 3, no. 1256850.
- Jaspal, Rusi, and Brigitte Nerlich. 2017. "Polarised Press Reporting About HIV Prevention: Social Representations of Pre-Exposure Prophylaxis in the UK Press." *Health* 21, no. 5: 478-497.
- Jones, Jess. 2017. "Bare Necessities: PrEPand the Rise of Condomless Sex." *Star Observer*, December 1.
- King, Nathan. 2014. "Are Health Care Providers Prepared?" *Clinical Correlations* (September 24).
- Koester, Kimberley A., et al. 2014. "Qualitative Findings from the Iprex Open Label Extension (Ole) in the Us." Paper presented at the 20th international AIDS conference, Melbourne, Australia. http://www.natap.org/2014/IAC/IAC 91.htm.
- Krakower, Douglas S, et al. 2020. "Tenofovir Alafenamide for HIV Preexposure Prophylaxis: What Can We Discover About Its True Value?" *Annals of Internal Medicine* (Jan 14). http://dx.doi.org/10.7326/M19-3337.
- Lune, Howard, and Bruce L. Berg, eds. 2017. *Qualitative Research Methods for the Social Sciences*. Harlow: Pearson.
- Marcus, J. L., et al. 2016. "Preexposure Prophylaxis for HIV Prevention in a Large Integrated Health Care System: Adherence, Renal Safety, and Discontinuation." *Journal of Acquired Immune Deficiency Syndrome* 73, no. 5 (Dec 15): 540-546. http://dx.doi.org/10.1097/QAI.000000000001129.
- Marcus, Julia L, et al. 2013. "No Evidence of Sexual Risk Compensation in the Iprex Trial of Daily Oral HIV Preexposure Prophylaxis." *PLoS One* 8, no. 12: e81997. <a href="http://dx.doi.org/10.1371/journal.pone.0081997">http://dx.doi.org/10.1371/journal.pone.0081997</a>.
- McCormack, Sheena, et al. 2016. "Pre-Exposure Prophylaxis to Prevent the Acquisition of HIV-1 Infection (Proud): Effectiveness Results from the Pilot Phase of a Pragmatic Open-Label Randomised Trial." *The Lancet* 387, no. 10013: 53-60. http://dx.doi.org/10.1016/s0140-6736(15)00056-2.
- Molina, J. M., et al. 2015. "On-Demand Preexposure Prophylaxis in Men at High Risk for HIV-1 Infection." *New England Journal of Medicine* 373, no. 23 (Dec 3): 2237-2246. http://dx.doi.org/10.1056/NEJMoa1506273.
- Morris, Paul, and Susanna Paasonen. 2014. "Risk and Utopia: A Dialogue on Pornography." *GLQ: A Journal of Lesbian and Gay Studies* 20, no. 3: 215-239.
- Myers, Julie E., and Kent A. Sepkowitz. 2013. "A Pill for HIV Prevention: Déjà Vu All over Again?" *Clinical Infectious Diseases* 56, no. 11: 1604-1611.
- Peabody, Roger, and Will Nutland. 2018. Questions and Answers on PrEP.
- Preciado, Paul B. 2015. "Condoms Chimiques." Libération, June 11.
- Rhoden-Paul, Andre. 2019. "PrEP: The Battle to Access 'Game-Changing' HIV Drug." *BBC News*, January 11, <a href="https://www.bbc.com/news/uk-england-46653462">https://www.bbc.com/news/uk-england-46653462</a>.
- Ryan, Kathleen, et al. 2019a. "Results from a Large Australian PrEPDemonstration Study: Discontinuation and Subsequent HIV and Other Sexually Transmitted Infection Risk." Paper presented at the Tenth International AIDS Society Conference on HIV Science, Mexico City.
- Ryan, Kathleen, et al. 2019b. "Results from a Large Australian PrEPDemonstration Study: Discontinuation and Subsequent HIV and Other Sexually Transmitted Infection Risk." Paper presented at the Tenth International AIDS Society Conference on HIV Science, Mexico City, July 22.

- Seitz, Sally. 2015. "Pixilated Partnerships, Overcoming Obstacles in Qualitative Interviews Via Skype: A Research Note." *Qualitative Research* 16, no. 2: 229-235. http://dx.doi.org/10.1177/1468794115577011.
- Spieldenner, Andrew. 2016. "PrEPWhores and HIV Prevention: The Queer Communication of HIV Pre-Exposure Prophylaxis (PrEP)." *Journal of Homosexuality* 63, no. 12: 1685-1697. http://dx.doi.org/10.1080/00918369.2016.1158012.
- World Health Organisation. 2017a. Who Implementation Tool for Pre-Exposure Prophylaxis (PrEP) of HIV Infection. Module 1: Clinical. Geneva: World Health Organisation.
- World Health Organisation. 2017b. Who Implementation Tool for Pre-Exposure Prophylaxis (PrEP) of HIV Infection. Module 11: PrEPUsers. Geneva: World Health Organisation.
- Young, Ingrid, et al. 2020. "Configuring the PrEPUser: Framing Pre-Exposure Prophylaxis in Uk Newsprint 2012-2016." *Cult Health Sex* (Apr 7): 1-16. http://dx.doi.org/10.1080/13691058.2020.1729420.

## vi Original in French:

La pilule et le Truvada partagent un même mode de fonctionnement: ce sont des préservatifs chimiques conçus pour prévenir des "risques" pendant un rapport sexuel, peu importe que ce risque soit un grossesse non désirée ou la transmission du HIV.

## vii Original in French:

Par ailleurs, avec les préservatifs chimiques, la décision de l'utilisation ne se prend plus durant l'acte sexuel, mais à l'avance, de telle facon qu'en avalant la molécule, le consommateur

<sup>&</sup>lt;sup>i</sup> This paper uses the term 'gay men' (as opposed to 'gay, bisexual and men who have sex with men' [GBMSM]) because available research suggests that 'bugchasing' is a phenomenon limited to 'gay men'. (See Garcia Iglesias 2020a,b). Bugchasing has a complex relationship with barebacking. While they share many similitudes (particularly because both practices effectively carry out the same sexual acts of condomless anal intercourse), this paper separates them. Bugchasing is the eroticizing of HIV, whereas barebacking is the eroticizing of condomless anal intercourse among gay men. This separation is necessary because bugchasing remains much more marginal and tabooer than barebacking, and thus the data of this paper should not be assumed to include barebacking. See Dean (2009) and Gonzalez (2010, 2012) for further work on this separation.

ii These are pseudonyms.

<sup>&</sup>lt;sup>iii</sup> PrEP is most frequently identified with its first formulation, a combination of emtenofovir disoproxil fumarate with emtricitabine (TDF–FTC) sold by Gilead under the brand name *Truvada*. Generic versions are widely available. More recently, a combination of enofovir alafenamide with emtricitabine (TAF–FTC) under the brand name *Descovy* (also by Gilead) has been touted as equally effective but safer (Krakower et al. 2020).

iv Efficacy refers to an intervention's capacity to produce the intended effects under ideal circumstances (such as full adherence during a trial). Effectiveness refers to that intervention's capacity to produce desired effects under 'real world' circumstances. PrEP is highly efficacious but, since it is burdened by low adherence, may not be effective in all contexts.

VPEP (post-exposure prophylaxis) is the use of antiretrovirals as prophylaxis after exposure to HIV: in practice, this means that HIV negative people who may have been exposed to HIV in the last seventy-two hours, may receive a course of antiretrovirals to prevent them from developing an HIV infection. TasP (treatment-as-prevention) is use of antiretrovirals to prevent those infected with HIV to pass the virus on others by helping them attain an undetectable viral load. Undetectability is the situation where a HIV positive person, through the use of antiretrovirals, manages to significantly control the replication of the virus in their bodies, being unable to pass it onto others.

construit sa propre subjectivité dans une relation temporelle de projection dans le futur: il s'agit de transformer par l'ingestion du médicament son temps de vie et la totalité de son corps, ainsi que sa propre représentation, sa perception des possibilités d'action et interaction.

viii This process is by no means unique to bugchasers, current research on sexual and reproductive health, for example, has evidenced how healthcare decision-making around abortion is also influenced by fantasies and desires, see García-Iglesias and Strong (2021).

<sup>&</sup>lt;sup>ix</sup> Risk compensation refers to the theory that being on PrEP will generate a sense of safety among people that will encourage them to engage in perceived riskier behaviors.