

Internet-Based Access to PrEP in the U.S.: A “Critically Applied” Approach and the Symbolic Effects of a Clinical-Technological Assemblage

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By

Introduction

“I’d been trying to get PrEP through my physician at the time, and ...I had to print up all these studies and all the prescription information because my doctor was like, ‘Well, you don’t have HIV.’ And I’m like, ‘I know. That’s the point. I don’t want to get it.’ And he’s like, ‘Well, [Truvada] is not for that.’ And I’m like, ‘Yes, it is!’ ... [Physicians] have no problems doing STI testing. They had no problems answering questions about STIs. But like I said, if it came down to being, like, anything with HIV/AIDS, that was where I was always hitting the wall. I was, like, I don’t understand. Why are you guys pushing back so hard on this?”
(P24)

Lack of access to knowledgeable providers who are willing to prescribe pre-exposure prophylaxis (PrEP) for HIV has been cited as a barrier to uptake in the US for years (Calabrese, et al. 2016; Krakower, et al. 2014), and remains a challenge for some patients, as the above quote illustrates. Other documented barriers include lack of awareness of PrEP, lack of access to or difficulty accessing care, fewer resources to pay for out-of-pocket expenses associated with PrEP (e.g. required laboratory testing), racism in medical contexts, and perceived or experienced stigma around same-sex attraction, immigration status, and other characteristics (Golub, et al. 2013; Martinez, et al. 2016; Mayer, et al. 2018; Pinto, et al. 2018; Underhill, et al. 2015). These barriers may be particularly acute for so-called “key populations”—those most likely to contract HIV. In other words, although PrEP has been called a “game changer”(Landers and Kapadia 2017) in HIV prevention, many of the structural vulnerabilities (Rhodes, et al. 2012) that anthropologists recognize as long having shaped the HIV epidemic are at work (Moyer 2015), making “changing the game” more difficult for some patients than for others.

Without assuming that pharmaceutically-based HIV prevention is attractive

to everyone, the fact that some people wish to take PrEP but find their access blocked is a clear issue of health equity. In discussions of how to move forward with PrEP implementation in the US, one oft-mentioned avenue is technology-based approaches (Sullivan and Siegler 2018), specifically telehealth, or the support and provision of clinical health care and health services through electronic information and telecommunications technologies. Telehealth, though not a panacea, seems particularly well-suited to connect potential PrEP users to willing prescribers who are competent in addressing sexual health, history, and risks, thereby avoiding burdensome travel requirements and stigmatizing interactions.

A desire to study telehealth and advance equitable access to PrEP led to a research partnership with Nurx, a start-up company based in San Francisco that is sometimes called “the Uber of birth control.” The company offers web-based counseling, prescription, and home-delivery services for PrEP in 24 US states and the District of Columbia. Our initial research objective was simply to understand how clients made sense of this “internet-based” experience. We pursued both applied and theoretical ends: we took an implementation science approach to identifying potential improvements to the service, and also considered what Nurx might have to teach us as a case study in the reciprocal and ongoing configuration of users and technologies (Holt 2015).

This research employed electronic chart review and semi-structured telephone interviews with clients who requested (though did not necessarily receive) PrEP through Nurx. Sampling so-called “PrEP requesters” enabled us to examine both the experience of completing the envisioned service cycle, and the barriers or circumstances that might prompt a prospective user to initiate but desist from engagement with the service. This discussion draws on thematic analysis of materials from 31 PrEP requesters in CA, NY, IL and FL, interviewed between April-August 2017. Participants were racially and ethnically diverse, predominantly cis-gendered men, highly educated, aged 30 or younger, who self-identified as gay.

Conceptualizing Nurx

The following service flow describes how Nurx users typically accessed PrEP online: In most cases, users became aware of Nurx through ads on social media, or an internet search about PrEP. They then visited the Nurx website and submitted a request for PrEP, which involves answering screening questions and uploading insurance information (if available). These materials were reviewed by Nurx personnel, including a physician who, for suitable candidates, transmitted orders for bloodwork to a lab chain with locations in the client’s area (e.g., Labcorp). Users then visited

a local lab to have required testing done. Results were electronically transferred back to Nurx, where a physician reviewed them. For users with negative HIV tests, a prescription for PrEP was transmitted to a participating pharmacy, which dispatched the medication via FedEx. Every three months, users were reminded to submit a new request if they wished to continue PrEP, starting the cycle again.

We found it useful to conceptualize Nurx's PrEP service as an HIV technology, specifically, a clinical-technological assemblage. In this we follow Davis and Squire (2010:6), who state that HIV technologies are more than "apparatuses merely surrounded and modified by social formations," rather they are "simultaneously the cause and effect of society." Thus, "clinical-technological" is not intended to exclude the social—instead, we understand technologies to be inherently social. We also take a significant cue from Rosengarten and Michael (2010:167) who define an assemblage as "a dynamic involving interrelationships between heterogeneous phenomena." Nurx certainly qualifies, connecting humans in various roles across time and space through social, clinical, pharmaceutical, transportation, and information technologies. Thus, by "clinical-technological assemblage" we wish to denote a process in which this composite is held in fluid association. Our analysis suggests it is, in part, the simultaneous compositional complexity and fluidity of Nurx as an assemblage that allows it to meet a range of client demands that have previously gone unfulfilled by traditional clinical interactions.

Effects of Nurx as an assemblage

While there is more to say about Nurx as an assemblage, here we'd like to highlight its effects. In particular, we aim to reflect on preliminary analytical impressions regarding ways this assemblage might exert effects that feed back into and alter the context in which the technology is deployed.

Materially, blood samples are taken and tested, PrEP is delivered, money is exchanged, and infection is (ideally) blocked. At an individual level, getting PrEP to people who wish to use it, especially if they previously lacked access, is an important victory. Repeated for a sufficient number of individuals, this may be associated with a decline in new HIV infections, as seen in San Francisco ((SFDPH) 2018), fulfilling the public health vision for PrEP. As significant as these effects are, here we focus instead on how Nurx might be imbricated with the "symbolic life" of PrEP, which Auerbach and Hoppe (2015:3) assert "will become just as important as its clinical efficacy in shaping how communities engage with it."

At least for some Nurx users, involvement in this clinical-technological assemblage seemed to catalyze a metamorphosis of meaning, a

substantial revision to their notions of what PrEP *is*. In many client narratives, prior to Nurx, PrEP figured as challenging or impossible to obtain, medically complex, and prohibitively expensive. We address these attributes briefly in turn.

Users' perceptions of PrEP as challenging to obtain had often shaped by previous access attempts. The interviewee quoted at the outset of this article had requested PrEP from physicians in three different California cities, without success. Another Nurx user was dissuaded from following through on a PrEP request by a particular provider's inexperience with the drug. He recounted a clinic visit, during which the provider "got the binder, I guess, that they have for PrEP. And it had never even been opened. It still had the plastic wrap around it. And I was just shocked by this. So, I kind of just gave up on that" (P14).

The construction of PrEP as medically complicated occurred most often among Nurx users who were knowledgeable about PrEP follow-up lab testing requirements, or had some kind of biomedical training. One interviewee said simply, "This is something that seemed too complicated [to be accessed in an online format]" (P04). For other users, the perception of PrEP's complexity can arguably be attributed, in part, to the so-called "purview paradox" (Krakower, et al. 2014). For example, one interviewee recounted asking his primary care physician about PrEP and being referred to an infectious disease (ID) specialist. This physician was "super knowledgeable about it, and she ordered my lab work herself," becoming the patient's conduit to PrEP. After moving away from the area, however, he sought other options and began using Nurx, because "finding a GP, then being referred to an infectious disease specialist, that was totally not an option for me at that point" (P15). Across the data set, multiple interviewees mentioned they had heard obtaining PrEP required referral to an ID. As such stories circulate, they can create or reinforce the idea that PrEP is complicated medicine.

Finally, pre-Nurx, many users understood PrEP as expensive. As one interviewee remarked when asked about initial concerns: "Honestly, price. Just because I've read online, like on Facebook, and all that, that ...a bottle could cost \$2,000? (P05). Another participant, who had lost his public insurance, learned through Nurx of a program to help "low-income" individuals access PrEP. He explained, however, that "I kind of figured that I wasn't going to be able to qualify" so "I just completely stopped everything [and didn't] return the calls, or emails, or anything" (P22). Without substantial financial assistance, this interviewee assumed he couldn't afford PrEP.

In contrast, however, after using Nurx to request PrEP, many interviewees seemed almost to be talking about a different drug. PrEP had become

accessible, simple, and affordable, although it was often challenging to separate PrEP itself from its provision through Nurx. Incidentally, such an integrated assessment is what we might expect, given the conception that PrEP is one component of the Nurx clinical-technological assemblage. Overall, most interviewees described the “convenience” of Nurx as the most attractive element of the service. As one interviewee noted, he could now “[get PrEP] online through the comfort of my office or my own house” (P03). PrEP had become easy to access.

The interviewee who had initially felt PrEP might be medically “too complicated” for an online format summed up his experience by saying, “This service was like a dream. This really was perfect for my needs” (P04). Another man, when asked what might prompt him to discontinue PrEP, spun out a couple of unlikely and “pretty extreme” hypothetical scenarios but then reflected, “Even at that point, I think that I would continue to use it, just because, why not?” (P25) Implicitly then, for this participant, PrEP is such a minimal burden it’s hard to justify giving up the protection it offers.

In addition, between insurance coverage (including public insurance) and Gilead’s patient assistance program (PAP), many interviewees paid nothing for PrEP. This was in part due to efforts on the part of Nurx personnel to help the service’s users reduce cost. One interviewee recounted having engaged in “a lot of back and forth [with Nurx about the PAP and ultimately]... I didn’t have to pay anything out of pocket” (P15). Thus, PrEP was usually not the high-dollar expenditure interviewees had previously feared.

Such wholesale symbolic reformulations, while striking, were not universal across the sample, but neither were interviewees’ service journeys all alike. Notions of potentiation (Davis and Squire 2010:185, 189) and co-constitution, in which users and technologies “can change each other and become something else when they are brought together” (Holt 2015:430), are helpful in elucidating how PrEP becomes something new/different as Nurx clients use the service to obtain it. In this, complexity and fluidity may again be key to Nurx *qua* clinical-technological assemblage, that is, a dynamic which both responds to and is partially constituted by “the social.” Users’ situatedness—in terms of, for example, previous PrEP access attempts or insurance status—*should* contribute to the process in ways that generate, according to Rosengarten and Michael, “many PrEPs, emerg[ing] out of and embody[ing] different associations that perform differently” (2010:167). Admittedly, this ontological revolution is occurring among only some of Nurx’s users—and certainly a tiny fraction of PrEP’s potential users. Nonetheless, such dynamics matter because these early adopters of online access may well will spread the “de-exceptionalized” version of PrEP within their social networks,

changing the context in which decisions about use and non-use are made.

The Value of a Critically Applied Approach

In [the introduction to this series](#), Whitacre invites contributors and readers alike to consider ways in which Scheper-Hughes's "critically applied medical anthropology" (Scheper-Hughes 1990) may serve as a guide for engaging with PrEP. In highly distilled form, the approach Scheper-Hughes advocates includes three central objectives: impeding medicalization, fostering medical pluralism, and encouraging "radical medicine," the latter being concerned with equity. We take up these challenges by highlighting ways the social is always already at play in PrEP and Nurx. Further, we remain open to multiple, even contradictory notions of what PrEP is. Finally, we engage in research with the objective to advance health equity as well as deepen our understanding of human engagement with biomedical technology. Taking a critical perspective allows us to see not only how "the practice of HIV prevention produces both subjects and technologies together" (Brisson and Nguyen 2017:4), but also what new avenues toward finally controlling the epidemic that production may open.

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