Crafting a 'critically-applied' PrEP collaboration in Memphis

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By

Encountering PrEP

I became interested in PrEP as an object of anthropological research on the L train between 1st and 3rd Avenues in Manhattan. It was the summer of 2014 and the global AIDS industry was humming with renewed biomedical triumphalism, hailing 'the end of AIDS' some argued PrEP and other scientific advances had made attainable (Kenworthy, Thomann, and Parker 2018). A bright pink poster advertising the Department of Health and Mental Hygiene's PrEP campaign was centered above the two-seat bench at one end of the subway car. It featured two black men dressed in matching sleeveless white tank tops and leaning into one another; one is laughing at something the other whispers into his ear. Splashed across the poster were the words **"WE PLAY SURE: PrEP + HIV TREATMENT + CONDOMS."** In another advertisement circulating on New York City buses and bus shelters, Gilead Sciences, Inc., the manufacturer of Truvada, also depicted two black men, one with his arm around the other, with the tagline "**We're open, not unprepared. We know who we are. And we make choices that fit our lives."**

I came to see these posters, as well as the television commercials and full-page magazine advertisements that have followed, as efforts to more fully "configure" (Holt 2015) the typical PrEP user in the minds of the public. Both seemed to intervene in the then widely circulating public discourse about those taking the drug – reframing them not as irresponsible "Truvada Whores" (Duran 2012), but as self-interested, rational, and responsible social actors who take preemptive, biomedical steps to secure a future without HIV. Anthropological engagement with PrEP scale-up efforts, I realized, could provide an important social critique of both neoliberal public health promotion and recent 'end of AIDS' discourse.

I have argued elsewhere (Thomann 2018) that campaigns like that of Gilead and NYC's Department of Health and Mental Hygiene represent the application of pharmaceuticals to what sociologist Barry Adam named the "neoliberal sexual subject" (Adam 2005). In Adam's configuration, the neoliberal sexual subject is a self-interested actor that shoulders

responsibility for their own risk and makes the “rational” choice to mitigate such risk by using condoms during anal sex. In its new configuration, this responsibilized sexual subject takes *pre-emptive*, biomedical action to mitigate HIV risk not through the exclusive use of condoms but by taking a daily pill. Recent science research has tackled the significance of this “game changing” drug for sexual risk and subjectivity. While behavioral science interests in PrEP had largely focused on barriers to uptake with the expressed goal of getting the little blue pill into the hands of “at risk” populations, contributions from social sciences have argued that these efforts focus too much on “getting drugs into bodies” (Auerbach and Hoppe 2015), calling instead for deeper contextualization of PrEP use and perceptions among users (Race 2015, Jaspal and Daramilas 2016,Young, Flowers, and McDaid 2016; Koester et al. 2017; Hughes et al. 2018; Pawson and Grov 2018). This body of work has posed a number of important questions, including how efforts to scale-up PrEP might further anchor already marginalized sexual subjectivities to increased risk of HIV (Dean 2009; Young, Flowers, and McDaid 2016); how the new biomedical technology blurs lines between sex, subjectivity, and science (Brisson and Nguyen 2017); concerns surrounding the commodification of HIV prevention (Young, Flowers, and McDaid; Thomann et al. 2018); and the impact such technologies might have on the work of community-based organizations (Garcia et. al 2015; Young 2015; Williams 2018).

In short, early anthropological engagement with PrEP – my own included – has largely focused on PrEP as a harbinger for the multiple and emergent tensions, meanings, and inequalities that accompany such magic bullet approaches to public health.

PrEP and its collateral benefits

While I quickly recognized PrEP and the politics around its scale-up as an opportunity to develop an important social critique, I did not immediately grasp how anthropological engagement with it might respond to Nancy Scheper-Hughes’ (1990) call for a ‘critically applied’ approach – one that allows for anthropological legibility in the clinical encounter while showing that what “really matters is outside it” (Whitacre, this issue). As I continued to watch the social life of PrEP unfold, I came to see that the NYC public transit advertisements centered the *social* benefits of PrEP – as a catalyst for increased intimacy in serodiscordant relationships and as holding the potential for those in non-monogamous relationships to draw up a wider range of prevention options. Rather than present its strictly biological benefits, the posters highlighted PrEP’s “collateral benefits” (Grant & Koester, 2015) – the social and emotional aspects that users often perceive as even more salient than biological protection from HIV. Instead of adopting condom-centric prevention messages, or moralistic ones promoting monogamy, the campaigns focused on “centering people’s

sexual and social goals" (2015, 7). As Grant and Koester (2015) argue, programming that overlooks the salience of these collateral benefits, or implicitly or explicitly discourages them, will likely undermine scale-up efforts.

By centering PrEP's collateral benefits, I seek to sit (uncomfortably) with "the unmet needs and frustrated longings" (Scheper-Hughes 1990, 71) that shape the structural vulnerabilities that shape the epidemic, while remaining attuned to the possibility that PrEP might "heal 'risky' sexualities" and open new possibilities for "hope, risk, pleasure and desire" (Whitacre, this issue). Critical medical anthropology is uniquely positioned to link the critical with the applied, using ethnography to demonstrate, for example, that PrEP uptake among communities most vulnerable to HIV mirrors larger disparities that shape the epidemic and thus frame discussions of access as matter of health equity (Hughes and Koester, this issue). The potential of a 'critically applied' approach to bridge the (assumed) gap between a social critique of PrEP and a commitment to promoting its equitable scale-up is the subject of my contribution to this important special series. How might anthropological engagement with PrEP "bridge the divide between 'critical' and 'applied' approaches" (Whitacre, this issue) that continue to splinter the subdiscipline of medical anthropology?

Carving out a space for the "jester" in a free PrEP clinic

Heeding the call of this Special Series to engage PrEP from a "critically applied" approach, this piece asks how thinking with the concept of "collateral benefits" – the social and emotional motivations for PrEP use that extend beyond the biological risk reduction it offers for HIV (Grant and Koester 2015) – can be mobilized in a way that is at once critical of the tensions described above while remaining engaged in the struggle for greater health equity. I ask how centering the social in an emergent research collaboration can begin to address "the basic incongruity between the interpretive ethnomedical and the positivist biomedical scientific paradigms" (Scheper-Hughes 1990, 65).

To write about PrEP in Memphis, not unlike Sandset's claims about Norway (Sandset, this issue), is to write about it from the margins – despite the metropolitan statistical area (MSA) having the eighth highest incidence in the United States, the city remains marginal in public discourse about and state-level investment in PrEP. There are only a handful of physicians known to prescribe PrEP and there is a dearth of information regarding what people say and think about PrEP's collateral benefits. Memphis fits the epidemiological profile of many other US contexts – men who have sex with men accounted for 53.4 % of new infections in 2015. In the same year, incidence rates among African

Americans were eight times higher than among whites and black men who have sex with men made up nearly 40% of new HIV diagnoses among African Americans. Despite recent efforts to scale-up PrEP scale use, less than 1,800 of the 77,000+ individuals filling a PrEP prescription in the US in 2018 lived in Tennessee (AIDSVu, 2018). These low rates of uptake must be understood in the context of the state's health insurance landscape. The Tennessee state legislature did not vote to expand Medicaid eligibility under the Affordable Care Act (ACA) and the state is currently seeking approval, along with seven other states, to institute a work requirement for TennCare (the state-run Medicaid program) recipients. 14% of Shelby County residents are uninsured (much higher than the 7% state-wide rate), making PrEP's nearly $2,000 price tag out of reach for many. Even for the insured, co-pays and lab costs (the cost of a quarterly panel can easily total $1,000) remain prohibitive.

I write this piece two weeks from the planned opening of a free PrEP clinic in Memphis, Tennessee, where I now live. More than five years after my encounter with a NYC subway poster and developing an interest in PrEP's neoliberal underpinnings, I was presented with a unique opportunity to conduct research *in* and *for* a community-based leadership team in a clinic setting. Paul, a white gay man in his early 40s who holds a senior leadership position in a local HIV organization, told me of plans to open The Corner – a one-stop shop for free, same-day access to PrEP. Additionally, The Corner will also provide free post-exposure prophylaxis (PEP), a service that my preliminary research has shown is difficult, and often impossible to access in Memphis, regardless of insurance status. In order to eliminate the extensive wait time interested patients faced for their first appointment with a PrEP provider, the clinic will accept walk in patients and will house its own Avita-run pharmacy. Recognizing that financial barriers have severally curtailed PrEP's impact in the city, the overall financial strategy of the clinic is to use the federal 340B Drug Pricing Program – a rebate program that makes Medicaid coverage of a manufacturers' drugs conditional on their agreement to provide qualifying entities access to the drug at significantly reduced prices. Individuals with insurance will also be able to access PrEP at The Corner and will be billed through their insurance company, providing additional revenue for the clinic's operational costs and, hopefully, its eventual expansion.

In addition to making PrEP access fast and free, The Corner has intentionally designed a space that tries to "overcome the stigma of a clinic." Well before my involvement, their leadership team had consciously distanced themselves from a typical medicalized setting – instead of a waiting room, the clinic will house a dedicated community event space and an art gallery.

When it opens, The Corner will be the first of its kind in the mid-South.

This research collaboration has led me to consider how PrEP might "expand the anthropological imagination" (Whitacre, this issue) of what a critically applied medical anthropology might look like – one that both grapples with the tensions raised by this new technology while also working towards greater access and equity.

By embracing what Scheper-Hughes described as the role of "the jester, the oppositional intellectual" (Hughes 1990, 66) in the clinic, I hope to both promote PrEP scale-up in Memphis among those who need (and want) it, while simultaneously leveling a "challenge to the perverse economic and power relations" (Scheper-Hughes 1990, 66) that have slowed its impact. Refusing the tendency to medicalize and privatize the social relations that contribute to the HIV epidemic in Memphis, this collaboration will instead center the social motivations of potential users and undermine the socio-economic inequalities that have limited its scale-up. This co-constructed collaboration reframes the clinic not as a space of alienating biomedical exceptionalism (Syversten, this issue), but as one with the potential to explore "new ways of addressing and responding" (Scheper-Hughes 1990, 70) to the inequalities that shape both HIV vulnerability and PrEP uptake.

Centering the social in the clinic

When I began research with Memphis-based PrEP navigators and prescribing physicians in 2018, I heard some version of four central concerns: First, PrEP providers and navigators described a lack of PrEP-awareness and perceived demand within Memphis' most vulnerable communities. The city's Centers for Disease Control and Prevention (CDC)-funded demonstration project had left many black residents with the impression that the drug was for white gay men. Bernard, a 25-year old black gay man currently on PrEP explained it this way: "At first it seemed like it was for the white gays. But my community, we didn't know much about it. No one was talking about it, really." Second, participants told me that the limited numbers of Memphians who are aware of PrEP and seek it out are often met with physician's ignorance of the drug, an unwillingness to prescribe it, and even outright stigma about why one would need to be on an HIV prevention drug. Jamar, a 26-year old black gay man and a PrEP navigator for a community-based organization explained, "The first time I asked a doctor they had no idea what I was talking about. I ended up educating them. When I switched doctors, my new one just asked me what that was all about and what I was up to that I needed to be on it." Third, even with the CDC-funded network of navigators equipped to link interested individuals to the half dozen known PrEP-providers, their clients – regardless of their insurance status – waited as long as two months for their first appointments. My collaborator Paul described realizing the limits he faced as a navigator, the first step in the process that would lead to the

opening of The Corner:

In the case of [PrEP provider name] and [PrEP provider name], depending on their client load, they may not be taking new clients. And if they are, if they can get you in, it's like 'oh you want to be on PrEP, great, we'll get you in in 2 months…the natural answer was to be a provider and not a PrEP navigator.

Fourth, even when navigators like Paul were able to overcome such obstacles by working their personal connections to get those interested in PrEP enrolled in services more quickly, the un- and under-insured were understandably daunted by the costs. James, a 28-year old black gay man and PrEP navigator explained, "I had a friend who stopped going to [well known PrEP provider] because his insurance did not cover it and it was like $300 for lab testing…he's like, those are the reasons he stopped going for his refills [and] for testing because his labs were too high." When potential users did have insurance, navigators and physicians spoke of prohibitive co-pays and lab prices. Rachel, a nurse-practitioner working in one of the few known private practices with a prescribing physician, explained:

These high deductible plans are kind of taken over and so they have to meet whatever the deductible is, their out-of-pocket expense, before their insurance will start paying anything. Other than the physical, which is free every year, and the labs related to the physical are covered – not free but they're covered because they're considered preventative care…But anything outside of preventative care, so those six-month check-in visits, they will be responsible for that entire office visit, and any labs associated with it.

Perhaps because of these community-held critiques regarding the social drivers behind slow PrEP uptake, centering the social and emotional factors that shape attitudes towards the drug has developed relatively naturally. Rather than emerging solely from my own priorities, politicizing PrEP access has been a co-constructed process with clinic staff and staff at community-based organizations. As I have carried out my ethnographic work – designing intake forms alongside clinic leadership, participating in trainings and workshops for clinic staff, and attending social events promoting the clinic – I have allowed myself to hope that such a collaboration, could lead to "subversive action towards greater health equity" (Syvertsen, this issue). By foregrounding potential users social and emotional goals and identifying barriers to such a framework, a 'critically applied' approach might promote scale-up effort without losing the critical edge that points to the "tragic experiences of the world" (Scheper-Hughes 1990, 71) that shape both HIV vulnerability and PrEP access.

A conversation starter: Remaining open to unknown PrEP's unknown possibilities

While PrEP messaging has often assumed that prospective users' overriding concern is HIV prevention, users often foreground their attraction to PrEP through other social and emotional goals related to their sexual health and wellbeing. Malika , a 31-year old black trans woman brought these goals into stark relief during a recent focus group discussion when she referred to PrEP as a "conversation starter." For Malika, a PrEP user herself, conversations around PrEP – whether with a potential partner met on a dating app or with a physician – opened the door to deeper discussions of pleasure, desire, and risk. Without proper attention to the social and emotional dimensions of PrEP users' experiences, implementation efforts could (wittingly or unwittingly) undermine the construction of an alternative, non-biological, and non-risk-oriented path to PrEP, thereby "foreclosing unknown possibilities" (Rosengarten and Murphy 2019). Through this nascent research collaboration, I have come to see the desire to practice an engaged and committed anthropology need not fall into the cynical trap of "pure" research that seeks solely to figure out what makes folks tick in order to get them on PrEP. Instead, I wonder whether purposefully thinking through PrEP's collateral benefits in a clinical setting might untether it from biomedical agendas and even reclaim medicine as a tool for human liberation (Syvertsen, this issue)?

Works Cited

Adam, B. D. (2005). Constructing the neoliberal sexual actor: Responsibility and care of the self in the discourse of barebackers. *Culture, Health & Sexuality*, *7*(4), 333-346.

AIDSVU (2018). Mapping PrEP: First ever data on PrEP users across the United States. Retrieved 10/28/2018 from https://aidsvu.org/prep/, 2018.

Auerbach, J. D., & Hoppe, T. A. (2015). Beyond 'getting drugs into bodies': Social science perspectives on pre?exposure prophylaxis for HIV. *Journal of the International AIDS Society*, *18*, 19983.

Brisson, J., & Nguyen, V. K. (2017). Science, technology, power and sex: PrEP and HIV-positive gay men in Paris. *Culture, Health & Sexuality*, 19 (10), 1066-1077.

Dean, T.(2009). *Unlimited Intimacy: Reflections on the Subculture of Barebacking*. Chicago, IL: University of Chicago Press

Duran, D. (2012). Truvada whores. *Huffington Post*, *12*.

Garcia, J., Colson, P.W., Parker, C. & Hirsh, J.S. (2015). 'Passing the Baton': Community-based Ethnography to Design a Randomized Clinical Trial on the Effectiveness of Oral Pre-exposure Prophylaxis for HIV Prevention among Black Men Who Have Sex with Men. *Contemporary Clinical Trials* 45 (2015): 244-51. doi:10.1016/j.cct.2015.10.005.

Grant, R. M., & Koester, K. A. (2016). What People Want From Sex and PrEP. *Current Opinion in HIV and AIDS*, 11 (1), 3.

Holt, M. (2015). Configuring the users of new HIV-prevention technologies: the case of HIV pre-exposure prophylaxis. *Culture, Health & Sexuality*, 17 (4), 428-439.

Hughes, S.D., Sheon, N., Andrew, E.V.W., Cohen, S.E., Doblecki-Lewis, S. & Liu, A.Y. (2018). Body/Selves and Beyond: Men's Narratives of Sexual Behavior on PrEP. Medical Anthropology, 37 (5), 387-400.

Jaspal, Rusi. (2016). Perceptions of pre-exposure prophylaxis (PrEP) among HIV-negative and HIV-positive men who have sex with men. *Cogent Medicine* 3 (1), 1-16.

Kenworthy, N., Thomann, M., & Parker, R. (2018). From a global crisis to the 'end of AIDS': New epidemics of signification. *Global Public Health*, *13* (8), 960-971.

Koester, K., R. K. Amico, H. Gilmore, A. Liu, V. McMahan, K. Mayer, S. Hosek, and R. Grant. (2017). Risk, Safety and Sex among Male PrEP Users: Time for a New Understanding. *Culture, Health & Sexuality*, *9* (12), 1301-1313.

Nguyen, V. K., Bajos, N., Dubois-Arber, F., O'Malley, J., & Pirkle, C. M. (2011). Remedicalizing an epidemic: from HIV treatment as prevention to HIV treatment is prevention. *AIDS*, 25 (3), 291-293.

Race, K. (2016). Reluctant objects: sexual pleasure as a problem for HIV biomedical prevention. *GLQ: A Journal of Lesbian and Gay Studies*, 22 (1), 1-31.

Rosengarten, M. and Murphy, M. (2019). 'A wager on the future': A practical response to HIV pre-exposure prophylaxis (PrEP) and the stubborn fact of process. *Social Theory and Health.* https://doi.org/10.1057/s41285-019-00115-y.

Scheper-Hughes, N. (1990). Three propositions for a critically applied medical anthropology. *Social Science & Medicine*, 30 (2), 189-197.

Thomann, M., Grosso, A., Zapata, R., & Chiasson, M. A. (2018). 'WTF is PrEP?': Attitudes towards pre-exposure prophylaxis among men who have sex with men and transgender women in New York City. *Culture, Health &Ssexuality*, *20* (7), 772-786.

Thomann, M. (2018). 'On December 1, 2015, sex changes. Forever': Pre-exposure prophylaxis and the pharmaceuticalisation of the neoliberal sexual subject. *Global Public Health*, 13 (8), 997-1006.

Williams, I., Papaloukas, P., Jaspal, R., & Lond, B. (2019). 'There's this glorious pill': Gay and bisexual men in the English midlands navigate risk responsibility and pre-exposure prophylaxis. *Critical Public Health,* 29 (5), 560-571.

Young, I. (2015) Imagining biosocial communities: HIV, risk and gay and bisexual men in the North East of England. *European Journal of Cultural Studies* 19 (1), 33-50.

Young, I., Flowers, P., & McDaid, L. (2016). Can a pill prevent HIV? Negotiating the biomedicalisation of HIV prevention. *Sociology of Health & Illness*, 38 (3), 411-425.

Matthew Thomann *is an Assistant Professor of Anthropology at the University of Memphis. His ethnographic work focuses on sexuality and the politics of health in sub-Saharan Africa and the United States, crossing subfields of medical anthropology, public health, and queer anthropology.* *He wishes to thank Dr. Ryan Whitacre for talking through these ideas and taking a lead on this rich Special Series.*

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