PrEP: Exploring a Painful Past

Since its approval for medical use in 2012, the treatment Pre-Exposure Prophylaxis (PrEP) has been hailed as a tool that will play a central role in ending the HIV/AIDS pandemic.[1] In scientific discourse, it has been especially celebrated for its ability to make the immune cells targeted by HIV hostile environments for viral reproduction with high specificity, a truly impressive feat. While PrEP certainly deserves some praise, portrayals of the drug that are entirely positive are myopic. Hiding behind these glowing narratives is an insidious history in which LGBT people and people of color were preyed upon in the drug development and testing process by the white, wealthy, and heteronormative. In order to construct a more balanced understanding of PrEP, particular attention must be paid to the historical transmission of HIV and to the political identities of those it has affected. When this information is sculpted into the contextual backdrop before which the development and consumption of PrEP is examined, it becomes clear that the drug comes from and has perpetuated violence against those who have consistently been pushed to the fringes of society. As such, PrEP has failed those most in need of HIV-related medical care and is not a sweeping force of good as it is often portrayed.

Although it is often ignored, a long history of HIV exists prior to its rise to infamy in the 1980s. The first human to have contracted HIV is thought to be a Kinshasan hunter who was exposed to a mutated version of the Simian Immunodeficiency Virus in approximately 1920.[2] Through his contact with others, HIV proliferated across sub-Saharan Africa, and by 1981, had reached the United States, as evidenced by the multiple gay men in California who had contracted rare and unusually aggressive lung infections and cancers.[3] Through its spread, HIV left behind a trail of thousands of bodies that had succumbed to common, relatively mild secondary illnesses because it left its hosts with non-functional immune systems.[4] In spite of

these abnormal clinical findings, however, HIV, which was still not actually recognized as a virus at the time, raised few concerns.[5]

In January of 1983, however, HIV abruptly began to elicit a widespread response: panic.[6] For the first time, cases of AIDS were discovered among white heterosexual women and their children, which suggested that HIV was transmissible through *all* sexual intercourse and mother-child contact.[7] While society was earlier confident that HIV was a disease that exclusively affected members of the gay community and those of lower socioeconomic status, these new cases shattered the long-held belief that the cleanly and "righteous" were immune to AIDS and induced a massive reaction from the international scientific community.[8] The following November, the World Health Organization, in response to what was quickly becoming a public health concern, held its first meeting to discuss the gravity of AIDS, and in 1984, the National Cancer Institute discovered the virus that caused the disease.[9] As soon as the traditional family unit was threatened by AIDS, sizeable amounts of time and money were poured into research with the intention of advancing HIV testing and treatment, and in 2007, early phase clinical trials were initiated for a revolutionary new medicine: PrEP.[10] Unlike the drugs that came before it, PrEP was designed to *prevent* infection by HIV, making it the first technology with the potential to stop the spread of HIV altogether.[11]

Since then, PrEP has proved to be immensely successful. Those who take it daily are at a 99% reduced risk of contracting HIV after exposure to it, and unlike most other drugs, it lacks a long list of major side effects.[12] In light of these achievements, it is tempting to enshrine PrEP on a pedestal of immunity. It still, however, requires interrogation, for the events that led to its creation and the responses they prompted are particularly worrisome. Why, when HIV was killing (almost) exclusively Africans, did no one care enough to keep a death toll?[13] Why, when

homosexual men were the first in the Western world to be infected, was HIV was simply written off as "gay related immunodeficiency," a supernatural punishment?[14] And why, when middle- and upper-class heterosexual white women began to be affected, was it immediately and finally clear that action was necessary?[15] For nearly sixty years, HIV exclusively ravaged the communities that have historically been regarded as disposable, uncivilized, and morally aberrant, thus making it easy for the privileged, those with resources that could be mobilized against HIV, to ignore it. To garner attention, HIV had to infiltrate the lives of the "correct" people. Thus, PrEP is a technology that owes its very existence to the notion that certain lives are inherently more valuable than others. From its inception, PrEP was not intended to assist those who were hit the hardest by HIV.

Unfortunately, PrEP's problematic ties with the marginalized are not severed at the dismissal of their plight but extend into the clinical practices that led to its creation. The bodies that were left to face the initial brunt of the HIV pandemic alone later became sites of experimentation for the pharmaceutical companies that were developing PrEP.[16] According to the National Institutes of Health, drawing on results from across seven different studies, at least 85% (15,010 out of 17,509) of the individuals involved in the initial wave of clinical trials for various forms of PrEP were high risk women, transgender women, and men who have sex with men from sub-Saharan Africa, South America, and Southeast Asia.[17] To worsen matters, many of these test subjects were involved in Phase II clinical trials, which means at the time of their participation, the *only* known information about PrEP was that the dose that was being administered was not thought to be lethal nor cause debilitating side effects. The efficacy of PrEP, though, was not certain.[18] Consequently, researchers administered placebos to approximately half of the patients in the trial, thereby thrusting them into conditions under which

they were likely to contract a life-altering disease in order to better understand their drug.[19] PrEP's origins are further complicated as more research reveals that clinical trials in Africa have sometimes failed to obtain the informed consent of the enrolled. Often, those involved were unaware that they were able to withdraw from a clinical trial at any time and that such withdrawal would not jeopardize any subsequent medical care that they might need.[20] In addition, many study participants did not understand that randomization would determine if they received a placebo nor that by participating, they were unlikely to be cured of AIDS or receive any supplementary medical benefits.[21] As it is nearly impossible to imagine that subjects from wealthy nations with robust medical infrastructure would endure such treatment, the remapping of medical testing onto the less affluent and less visible speaks to the problematic history of the drug's production. In response to this abuse, it logically follows that PrEP should be made extremely available to the neglected populations who made its development possible, but those that were deceived into becoming lab rats and reduced to petri dishes have received no reparations. The crimes against PrEP's victims have been erased by the very hands that inflicted them.

Rather than receiving any form of compensation, the majority of the LGBT community and people of color are denied access to PrEP, especially in the United States.[22] For the uninsured, Truvada (the only form of PrEP that has been approved by the FDA for consumption), can cost up to $2,000 monthly, an expense that is simply unreasonable for so many.[23] In the regional South, where HIV infection rates are documented to be higher than in the rest of the country, some states have not adopted fully developed Medicaid programs, thus barring those who rely on public insurance from obtaining the care that they need.[24] Even those on private health insurance plans are met with obstacles, as many providers consider Truvada to

be a “special” drug and thus charge high copays and/or do not cover the lab work and quarterly physician evaluations that are required to take the drug.[25] Collectively, these restrictive policies result in approximately 80% of the more than one million people at high risk of contracting HIV in the United States living without the only drug that can help them.[26] While some are hopeful that a generic version of PrEP (which is intended to enter markets in 2020) will force the price of all PrEP medications to fall, an appreciable decrease in the cost of the medication will only come after a number of different generic versions are in competition.[27] Thus, those that need PrEP immediately will still likely to have wait several years until they are able to afford it. Furthermore, as Gilead Sciences’, patent on Truvada nears its expiration date, the pharmaceutical company is preparing to release a new version of PrEP, Descovy.[28] While this new drug does not necessarily out-perform Truvada in preventing HIV, it has been shown to minimize Truvada’s side effects, renal and bone damage, which physicians argue is essential for maintaining long-term use of the medication.[29] If Gilead Sciences’ replicates its previous price-setting practices, this drug will also be too costly for those who need it most, and the marginalized will underserved yet again.

That a malicious side of PrEP exists and is buried away should not be surprising at this point in time. Throughout history, the generation of medical knowledge has frequently come at the expense of the dehumanized, specifically the black body. Dr. James Marion Smith (the man known as the father of modern gynecology), for example, earned his title by repeatedly dissecting the reproductive systems of non-consenting, fully awake slave women in order to perfect a repair technique that was needed to treat his white, female patients.[30] In 1932, the U.S. Public Health Service permitted physicians in Tuskegee to deny 400 black men treatment for syphilis so that they could collect information on the progression of the disease in those who

were “inherently” sexually perverse.[31] These practices, although they have been criticized, still established a robust precedent which allowed for the biological colonialism tied to PrEP. With this troubled history laid bare, there is a significant dilemma: What should become of PrEP? While it would be nonsensical to abandon it completely, to continue to use it as if nothing is wrong would mean denying the reality that some were made invisible and then exploited in the process which created it. The first half of a potential solution is consumer-led demand. Those who are privileged enough to have access to PrEP should demand that pharmaceutical companies make it more accessible to the communities that were intentionally harmed both when the medication was actively not made *and* made. Second, a sweeping educational campaign is in order, for rectification of the damage packaged into PrEP is not enough to make up for a long history of injustices alone nor will it prevent those that have yet to – but will – come. The exploitation narrative that runs through biomedicine must be ruptured, and this may only come about if people are made aware of its existence. Action here is critical, for if we do nothing at all, then we are complacent. And if we are complacent, we are part of the problem.

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Implosion Essay Prompt

For your final essay, you will be writing a research paper in which you “implode” an object of technoscience. To implode a technoscientific entity is to study the conditions in which it was imagined, designed, constructed, circulated, used, and even destroyed. Implosion will not only expose the sociohistorical contexts out of which the object emerged, but it will also reveal how the object itself influenced sociocultural formations.

The artifact you choose should be as specific as possible. For example, rather than imploding cell phones, you should implode the iPhone 5s; rather than imploding nuclear bombs, you should implode the Y-1561 plutonium implosion device. Considering the design practices that distinguish specific models from previous or later iterations will allow you to make connections and assumptions regarding why individual choices were or were not made.

As part of your preliminary research for this essay, you will subject the object you choose to two analytic methods: Marshall McLuhan’s “tetrad of media effects” and Joseph Dumit’s “implosion map.” The frameworks devised by McLuhan and Dumit will help you unpack the sociohistorical forces underpinning your artifact, and following the steps they prescribe should direct you toward making an argument about how the object’s design, production, and uses engage with the social and the political spheres. After you have constructed a tetrad and implosion map for your object, you will develop a critical argument that attends to the social and political life of your artifact and write a 1700-2000 word essay.