

HIV Biomedical Prevention Science and the Business of Gender and Sexual Diversity

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ABSTRACT

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This dissertation examines the political economy of HIV biomedical prevention research—largely designed in the global North but conducted in the global South—and its implications for people of diverse genders and sexualities. As a recognized global leader in HIV biomedical prevention research among people categorized as men who have sex with men (MSM) and transgender women, Peru offers a key site in which to explore the increasing focus on gender and sexual identity as a strategic area for extractive research practices. This phenomenon has become particularly visible in the epidemic's 4th decade, which has emphasized the pursuit of biomedical prevention strategies. Building on nine years of previous experience working inside HIV biomedical prevention studies, this project involved 24 months of ethnographic research, including participant observation; 110 interviews with scientists, study staff, and research subjects; 10 focus groups; and analyses of relevant scientific publications.

This study presents four key findings. First, US and Peruvian researchers' historical and continued entanglement primed Peru to become a hotbed of HIV biomedical prevention research. In this context, population categories imported from the global North have served as powerful tools to sustain a booming local research market, which produces data that aligns with the global demands of the HIV industry. Second, on the ground, research begets more research rather than institutionalized HIV prevention technologies, creating a sustained enterprise in which issues of compensation, value, and labor shape the science. The commodification of gender and sexually diverse identities operates here in two ways: as a mechanism to access particular kinds of bodies

and associated HIV risk data, and as a mechanism by which to claim expertise in the HIV prevention research industry for both researchers and community members. Third, Peruvians classified as MSM and transgender women are afforded only temporary access to cutting-edge strategies to prevent HIV, limited to study participation. The result is a sustained pool of people in need of HIV care primed to support the HIV biomedical research economy. Finally, this project illuminates a key paradox within the industry's contemporary focus on gender and sexual diversity in HIV prevention science. This focus creates the impression that progressive health politics marked the field, while obscuring and absolving ongoing forms of exploitation and unequal gains embedded within it.

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Chapter 1

Introduction

I moved to Lima in January 2010 at a moment of great global enthusiasm around advances in HIV biomedical prevention research. Many of these advances were due to research conducted in Peru, and I was lucky enough to see first-hand how HIV science was done from my vantage point in Lima. My auspicious position was happenstance. After college, I worked as a case manager for people living with HIV in San Francisco. My interest in research combined with being a native Spanish speaker led to the opportunity to live and work in Peru, first as a Rotary International fellow and then as a research assistant for University of California, Los Angeles's outpost in Lima. I would only later recognize the value of living full-time in Lima for the next two years. During that time, two major transnational clinical trials were underway, testing a therapeutic medication to prevent HIV. These studies, among the first to test pre-exposure prophylaxis (PrEP) in humans, focused on people deemed "most at-risk" for infection, specifically men who have sex with men (MSM) and transgender women.

The first study, iPrEx (short for its Spanish name, *Iniciativa Profilaxis Pre-Exposición*), was initially only planned to operate in Peru. However, enthusiasm for PrEP led to public-private partnerships, including a joint effort between Gilead Pharmaceuticals (the producers of PrEP) and the US National Institutes of Health, and by 2007 the study had grown to also include sites in Ecuador. By 2008, iPrEx expanded further, and PrEP was being tested among people classified as MSM and transgender women in Brazil, Thailand, South Africa, and the United States. While 56% of iPrEx's global participant sample came from Peru (Grant et al., 2010), iPrEx proved to be a global watershed moment for HIV prevention research. It subsequently set

the stage for a bustling growth industry around researching biomedical HIV prevention with pharmaceuticals that targeted people of diverse genders and sexualities – a departure from an earlier research emphasis on treatment. This dissertation examines iPrEx and subsequent related studies carried out in Peru to question how this global shift in the 4th decade of the HIV and AIDS epidemic impacted the lives of people involved in contemporary HIV science.

By the time I arrived in Lima, iPrEx was concluding recruitment and an ensuing study, iPrEx OLE (Open Label Extension), was being planned. Because I was new to HIV biomedical research, the first thing I did was learn about these studies and try to determine who the key investigators were. Serendipitously, I had focused on Mafia Studies within an Italian Studies major as an undergraduate at a small liberal arts college in Colorado, and I inevitably began to analyze HIV research networks in Peru through a related lens. Though seemingly disparate topics, in fact there were quite a few connections between the Cosa Nostra and how research clusters operated in Lima. The researchers, of course, are not a criminal mafia. They did not and do not engage in crime and violence to exact power. But it is possible to consider the kinds of linkages between in them in a way that resembles the networks underpinning the Italian mafia structure.

Biomedical research is hierarchical, and the top power brokers are almost never fully visible. Indeed, it was not until I returned to the United States two year later to begin a master's degree in public health that I recognized the centrality of US training, and of US researchers, in leading biomedical research efforts in Peru. Furthermore, I realized that global North money was deeply entangled with the type of science being done and the scientists selected to do it. In Peru, the competition to gain access to this international network and to global North funding was palpable, and created longstanding divides between research clusters, often to the detriment of

the research itself. As a fellow and then research assistant, I was part of one such prominent research cluster – positions that explicitly granted me access to meetings and conversations that taught me to identify and differentiate the leading networks of US and Peruvian investigators, and strategically negotiate the rifts between them.

In November 2010, iPrEx results were published and garnered international attention, most notably, from then-president of the United States, Barack Obama, who defined iPrEx as “groundbreaking research on HIV prevention” (Office of the Press Secretary, The White House, 2010). Foreshadowing the robust industry that would develop not only around biomedical HIV prevention research but also around targeting most at-risk populations, President Obama continued, “While more work is needed, these kinds of studies could mark the beginning of a new era in HIV prevention” (Office of the Press Secretary, The White House, 2010). The iPrEx study underpinned FDA approval, CDC and WHO guidelines, and other policy changes, ushering in an era of PrEP as the primary strategy to therapeutically prevent HIV among those who are HIV-negative but “*most* at-risk” for infection.

Against the backdrop of iPrEx and iPrEx OLE, the last months of 2010 and the first months in 2011 coincided with an important domestic research event in Peru: a new sentinel surveillance program. Since the introduction of HIV biomarker data in 2001, a series of Demographic and Health Surveys (DHS) had been the leading source of procuring data on HIV at the national level. Though there is an active DHS monitoring system in Peru, these surveys did not assess HIV biomarker or behavioral data among populations considered most at-risk for HIV. For this reason, the Peruvian HIV Sentinel Surveillance program had separately conducted routine surveillance of MSM since its inception in 1996, and, as of 2011, for the very first time, included transgender women as a separate at-risk category. Interestingly, the lead investigators of

the iPrEx and iPrEx OLE studies spearheaded this surveillance initiative, and it also forced numerous research clusters to collaborate.

In my position working for US researchers in Lima, I attended leadership meetings but spent most of my time with fieldworkers tasked with administrative duties related to study implementation. About six months into my stay, there was an abrupt shift as I began to notice efforts to count and enumerate risk among transgender women as a separate most at-risk category, whereas earlier it had been subsumed within the category MSM. This was not an organic transition, but rather, as I observed, one met with resistance from both experts and fieldworkers. I did not question this shift until I began to accompany fieldworkers in administering the surveys. Since they were incentivized monetarily for the quantity of participants enrolled, it was common practice for fieldworkers to quickly explain eligibility criteria and study procedures in order to meet their quotas. Many people already understood the acronym MSM, so this category posed little trouble for fieldworkers. However, this was not the case for gender-diverse people, as many women that fieldworkers visually identified as transgender did not identify as transgender but, rather, self-identified as *travesti*. Because *travesti* was not an option for fieldworkers to check on the enrollment forms, they subsequently had to either contradict a *travesti* woman by stating, “No, usted es transgénero” (No, you are transgender), or simply mark “transgender” and begin enrolling the potential participant.

I saw first-hand how researchers labeled, classified, and counted people with diverse and fluid genders in the context of scientific practice. Although unsettled by what seemed to be arbitrarily rigid definitions that were often at odds with how people self-identified, I did not question this observation at the time. I was on my own trajectory, having been recently accepted into the Harvard School of Public Health to work towards a master’s degree. I consequently left

for Boston in 2012, but continued to periodically work in Lima on numerous studies. Since that time, I have been fortunate enough to spend an average of three to five months a year in Peru to continue this work.

These inconsistencies around categorizing gender and sexuality marked my time in Lima and fueled critical questions during my master's program. On the one hand, I was learning about study design and sampling methodology, but on the other, I had first-hand knowledge of the messiness of research that conflicted with the clean examples presented in my classes. As I studied the tools for epidemiologic analysis and the importance of categorization, I began to not only verbalize these tensions, but also show how they influenced data. For example, back in Peru, I created and implemented surveys that followed a global North rubric, separating sexual orientation and gender identity to account for the diversity among MSM and transgender women. But although the categories followed this logic and we also adjusted them to include locally relevant terms, such as *travesti*, confusion abounded during implementation. Some people on the transfeminine spectrum identified as transgender, others as *travesti*, and others as cisgender men. Furthermore, most mentioned having sex with men when discussing intimate practices, but some selected homosexual and others heterosexual when asked to define their sexual orientation. While this is an example of different participants answering questions to reflect their own identities, in statistical analysis it poses the issue of measurement error. If people do not respond consistently, what are we measuring?

Ultimately, recognizing these challenges with data and associated politics to achieve measureable impacts of and for HIV science led me to question the effects of these scientific initiatives and my role within them. Intentionally transitioning away from my master's training in social epidemiology, I sought interdisciplinary doctoral training as a social scientist to equip

myself with the tools to analyze this scientific field and its challenges through a critical ethnographic lens. Almost a decade later, I have had the opportunity to work with a diverse range of people linked to this field in various ways, including activists, sex workers, peer health promoters, researchers, and medical doctors. They inhabit different spaces within the Peruvian and global HIV biomedical arena, from participants and researchers to those who reject and protest these types of studies.

Since first arriving in Peru in 2010, the research landscape has expanded rapidly, as a growing number of ongoing studies focusing on, and often competing for, MSM and transgender women participants have emerged over the past decade. It is critical to underscore the temporary nature of these studies. Typically, they last between three to five years, which means that therapeutic interventions and associated HIV care conclude at the study's end, including access to PrEP. While the results from iPrEx and iPrEx OLE in Peru were instrumental for the US FDA's approval of widespread PrEP use in 2012 (U.S. Public Health Service, 2018), Peruvian approval did not come until four years later (Avert, 2016). This meant that more than 1000 Peruvian study participants who had used PrEP as part of a clinical trial did not legally have access to the medication for more than four years after the study ended (whether or not they wanted to continue). My involvement in different studies and contact with repeat participants enabled me to witness the significant impact of being classified as "most-at risk," but simultaneously only eligible for short-term care.

Over the course of my time working in Lima, I benefitted tremendously from my position as an emerging American public health researcher linked to the region's top research clusters. I have held multiple positions with multiple responsibilities. Critically tracking my own involvement in and observations of HIV biomedical research studies, alongside the stories of

others touched by this industry, I am in a unique position to address a series of key questions about this field: What motivated the rise of HIV research targeting MSM and transgender women? How has this research shaped identity categories among these groups, and their understandings of themselves and their communities? How do they experience research participation, and how does the industry value participants and their labor? And what is the impact of HIV research on the care available to the groups it targets?

Research Context

Why Peru?

The initial reasons that led me to move to Lima and work on HIV biomedical trials predated any interest in graduate-level study or an eventual dissertation. It became clear many years later that my opportunity to do research in Lima was not random, as it had appeared to me, but due to existing US investments in HIV science and the growth of research post-iPrEx, both of which created an amenable environment to house and train students. As it turned out, my placement in Lima as a fellow and then UCLA employee was extremely timely to observe the rise of the HIV biomedical prevention research industry's focus on people categorized as MSM and transgender.

In many ways, Latin America¹ appears to be a success story when compared to other global regions, such as Sub-Saharan Africa and Southeast Asia, in terms of the burden and suffering caused by HIV and AIDS as well as responses to the epidemic (UNAIDS, 2015).

Indeed, early efforts from civil society and governments to provide universal access to

¹ Latin America is a fraught term and has been contested by a multitude of scholars. Following the work of Medina, da Costa Marques, Cueto, and Holmes (Medina, da Costa Marques, Cueto, & Holmes, 2014), I use it here to convey a political category rather than a homogenizing cultural identity.

antiretroviral treatment (ARV) for HIV and AIDS are among the factors contributing to understandings of success in Latin America (Smallman, 2012). The best example is Brazil, which led the way in enacting universal access to antiretrovirals on a global scale. Brazil's rapid action to manufacture and distribute generic ARVs illustrates the rise and power of civil society in addressing HIV treatment in the region via the exportation of ARVs to other resource-scarce countries in Latin America (Berkman, Garcia, Muñoz-Laboy, Paiva, & Parker, 2005; Oliveira Cruz, Kowalski, & McPake, 2004).

But while generic ARVs and large-scale access was a monumental development, it was a momentary success. By the early to mid-2000s, Latin America's ability to respond to the epidemic waned, but the perception of its success limited the region from receiving needed financial support from bilateral donors like the World Bank, USAID, PEPFAR, and the Global Fund, all of whom shifted their focus to other regions, primarily Sub-Saharan Africa. Without the flow of development aid for HIV, the major source of external support for HIV-related work came from science aid, meaning HIV and AIDS-related global public health research funding (e.g., US-based NIH funding, CDC, etc.).

Smallman's analysis (2012) of HIV in Latin America sheds light on the importance of civil society in many nations' post-dictatorship periods, which shaped effective responses to HIV and AIDS. In most of Latin America the HIV epidemic emerged during a period of democratization (Smallman, 2012). For example, in Brazil, the HIV epidemic emerged at the same historical moment that the Sanitary Reform Movement fought to include universal access to health services as a right for all Brazilians in the democratization movement against the military dictatorship (Berkman et al., 2005; Parker, 1990). Bringing together hemophiliacs, gay men, and the Sanitary Reform movements the initial response to HIV in Brazil was grassroots-

driven and framed by human rights principles (Bastos, Caceres, Galvão, Veras, & Castilho, 2008; Parker, 2003). Many of the same activists that led the initial response to HIV during the re-democratization process became incorporated into AIDS bureaucracies and into leading AIDS NGOs throughout Brazil, which led to the continued implementation of human rights principles in policy into the 21st century. Brazil's experience defying neoliberal policies that protect intellectual property and patents contributed to the country's position as a political economic influencer in the global South (Parker, 2008; Passarelli & Terto, 2003; Renata, Terto, & Pimenta, 2009).

However, starting in 1990, Peru's response to the epidemic was quite different and the exception in the region. Due to Alberto Fujimori's authoritarian rule, Peru's approach evolved from the top down, with evidence suggesting that Fujimori enacted "mass round ups of gays who were compelled to undergo HIV testing" (Smallman 2012, 182). Science aid also took on a much greater role due to early US investment and interest in supporting the Peruvian response to the epidemic. According to Cueto, the U.S. Navy Medical Research Institute Detachment (NAMRID) was the central institution facilitating HIV testing for large numbers of individuals deemed at-risk for infection. While NAMRID turned over operations to the Peruvian state in the early 1990s, the presence and prominence of a US biomedical research infrastructure has continued to influence the Peruvian response to the epidemic since 1983 (Cueto, 2001).

Today, Peru is a recognized "hot-spot" of a particular type of HIV biomedical prevention trials: clinical research focused on people categorized as MSM and transgender women (J. Cohen, 2006). The global public health epidemiologic literature offers a partial sense of why this is the case. The use of these categories has illuminated that the Peruvian HIV epidemic is characterized by a disproportionate burden of infection among MSM and transgender women.

HIV prevalence among these groups has been reported to range from 29.8% to 48.8% in Lima (Clark et al., 2013; Silva-Santisteban et al., 2012) as compared to 0.4% among the general population (USAID, 2008). Furthermore, epidemiologic research into the factors associated with HIV “risk” has highlighted a number of key behavioral and biological factors that seem to drive this disparity, including the prevalence of transactional sex practices (Silva-Santisteban et al., 2012), frequent condomless receptive anal intercourse (Cambou et al., 2014; Goodreau, Goicochea, Grantome, 2005; Perez-Brumer et al., 2016b), low incidence of HIV testing (Cambou et al., 2014; Duerr, Lama, & Sanchez, 2014; Silva-Santisteban et al., 2012), and sexual contact with partners of unknown HIV serostatus (Clark, Perez-Brumer, & Salazar, 2015; Clark et al., 2014).

However, these health statistics only tell one side of the story. They provide an individual-based epidemiologic profile that aligns more with the dominant global HIV research agenda than with the realities that directly affect the lives of Peruvians most impacted by the epidemic. This study seeks to do something quite different. It interrogates what these numbers mean in a moral, economic, and social sense. It also aims to analyze the complex performative processes involved in producing scientific knowledge – in this case, scientific knowledge about biomedical HIV prevention methods in relation to people that have been identified and classified as MSM and transgender women.

HIV as a Political Economy: Where Are We in the 4th Decade?

The 4th decade of HIV and AIDS has ushered in a new era of how scientific research is done, what technologies are at play, and among whom this research is conducted. To provide a window into the ongoing and evolving political economy surrounding the epidemic, this study

provides a critical reflection of the explosion of biomedical research among certain groups classified as at-risk for HIV. I argue that today there is a unique emphasis on enumerative evidence to assess risk profiles and intervene through the application of preventative therapeutic technologies (i.e., antiretroviral therapy for *both* treatment and prevention). Said differently, biomedical prevention among those understood to be *most* “at-risk” for HIV is novel to the 4th decade of HIV science. These essential components of how HIV science is conducted and how knowledge is produced are not entirely new. Rather, they have evolved and come to prominence in and around the 2010s. Against this backdrop, Peru is a salient case study to illustrate the ways in which the global South is increasingly utilized as a living laboratory among those most at-risk for HIV to test therapeutic HIV prevention innovation and despite the associated harms.

Having initially moved to Lima in early 2010, I actively observed the scientific practices and performances involved in the creation of “transgender women” as a research variable separate from MSM in HIV prevention science. Since that time, there has been much advocacy to justify and maintain these two scientific populations as distinct yet both understood as *most* at-risk for HIV. Interested in how decisions were made regarding the categorization of people of diverse genders and sexualities, I began to ask questions about the increasing focus on transgender women as a distinct population, apart from gay, bisexual, and other men who have sex with men (all categorized in HIV biomedical prevention research as MSM). These questions were never intended to invalidate transwomen’s womanhood, but rather to better understand the process of subjectification taking place through HIV prevention research (Foucault, 1982). These questions ground my ethnographic inquiry into the rise of research on people of diverse genders and sexualities and its relationship to the political economy of HIV prevention science.

In raising these questions, my analysis brings together sociological, science and

technology studies (STS), and queer studies frameworks for the study of HIV prevention science. As I detail in the sections that follow, my analysis is deeply indebted to and builds on three intertwined theoretical perspectives. In this first section, I draw on scholars theorizing the social construction of risk and the subsequent value derived from people scientifically understood to be at-risk for HIV. In the second, I draw on literature assessing governance and citizenship to question who is responsible for health in the context of offshored and temporary HIV prevention research. And in the third and final section, I build on scholarship chronicling the visibility of sexual rights in the 21st century and critiquing the imaginary of LGBTQ inclusion as progressive politics. Building off of this scholarship, this study advances understandings of how cataloguing high risk and the collection of increasing amounts of data from gender and sexually diverse communities has particular value in the 4th decade of the HIV industry. By paying explicit attention to which bodies and identities “count” and why, I illustrate how the contemporary focus on MSM and transgender women, categories created to define people at heightened biological risk for HIV, works to extend the scope of possibility for HIV biomedical markets.

Conceptual Frameworks and Contributions

The value of HIV prevention among the *most at-risk*

In conversation with the social scientific literature about the political economy of health, one of the central contributions of this study is that it brings to the fore myriad aspects of value that have spurred the growing HIV prevention industry, not only among people deemed at-risk for HIV, but now those *most at-risk*. To consider gendered and sexualized bodies and their value for the production of HIV prevention knowledge, I draw heavily on contemporary theorizations of bioeconomy and associated concepts (i.e., biovalue, biocapital, etc.) (Cooper & Waldby,

2014; Novas, 2006; Petersen & Krisjansen, 2015; Rajan, 2006). Central to this literature, as indicated by the prefix “bio,” is an emphasis on biology – and more generally life – as a lens through which health is understood (i.e., biomedicine), regulation and power are exerted over bodies and populations (i.e., biopower), and social realities and self-understanding are configured (i.e., biosociality) (Clarke, Mamo, Fosket, Fishman, & Shim, 2010; Lock & Nguyen, 2010; Rabinow, 1999; Rose & Novas, 2005). The work of Catherine Waldby (2002), Kaushik Sunder Rajan (2006), and others has also advanced the notion of biocapital by analyzing the emergence of commercial markets around and the commodification of human biological material (i.e., blood, tissues, cells, etc.). Notably, this scholarship is deeply indebted to Marxist understandings of value² and the Foucauldian notion of biopolitics³ (Birch & Tyfield, 2012).

This dissertation analyzes new forms of value-making in light of the shift from treatment to prevention *as* treatment among people categorized as *most* at-risk. To disentangle conceptualizations of value, I also borrow from Arjun Appadurai’s (1986) notion of “regimes of value.” In his formulation, defining commodities solely through economic value fails to account for cultural and political factors that also influence the complex process of infusing things with value. Appadurai argues that commodities circulate through multiple regimes of value, economic and otherwise, and “politics (in the broad sense of relations, assumptions, and contests pertaining to power) is what links value and exchange in the social life of commodities” (Appadurai, 1986, p. 57). Leveraging this framework, I assess commodities, capital, and labor as the means through which value is created in the process of doing HIV prevention science among people categorized

² These arguments are based on Marxist concepts of labor power and surplus value, as applied to biocapital. See Rajan (2006) pages 15-19 and 172-174 for more on capital materiality and abstraction. And Cooper and Waldby (2014) pages 10-14.

³ For further readings on the Foucauldian notion of biopolitics, see Peterson (2014) pages 113-114, 193 and Rose (2014) Chapter 1 pages 9-40. For an application of biopower directly in relation to sexuality and gender see Corrêa, Petchesky and Parker (2008, pp. 115-119).

as MSM and/or transgender.

This dissertation argues that the HIV industry's emphasis on biomedical prevention among populations deemed most at-risk – namely, people of diverse gender and sexual identities – must be understood in relation to the value that can be derived from these groups. Although deeply linked to material bodies, here “biovalue” also depends on gender and sexual identity. Moreover, this value extends beyond economic gains to incorporate social desirability, as research scientists value the construction of expertise related to HIV prevention science *and* the public perception that doing research “on” LGBT communities demonstrates progressive politics in action. Likewise, people of diverse genders and sexualities who are hired as study staff value the economic compensation of employment *and* the symbolic status of their professional position and recognition as a community leader. And people who participate in research as human subjects value access to (temporary) HIV prevention technologies *and* altruistic notions of helping their community by engaging in experimental trials.

This is not just an ethnography about the creation of gender and sexuality-based categories (see Valentine, 2007), nor about expanding categories of biomedical risk (Dumit, 2012; Waggoner, 2017). Rather, specific to the 4th decade of the HIV epidemic's focus on prevention, I argue that risk is just a starting point and, as this study chronicles, further value comes from branding people of diverse genders and sexualities as *most* at-risk for HIV. Understanding risk and counting those at-risk is not and has never been a neutral task. As Mary Douglas (1990) argues, meanings of risk that previously denoted chance have shifted in contemporary usage to be synonymous with danger and hazard (Douglas, 1990). Yet this is a hidden attribute, and risk “has the rhetorical effect of creating an aura of neutrality, of cloaking the concept in scientific legitimacy” (Lock & Nguyen, 2010, p. 305). By extension, scholars

have further argued that risk has been mobilized to justify modes of surveillance (Foucault, 1990; Lupton, 1997), and the emergence of at-risk populations, namely, people who are not yet sick but in need of medical intervention to prevent illness, reflects the expansion of medical reach in contemporary society (Greene, 2007; Rose, 2007).

Within HIV science, notions of being at-risk for HIV have been deeply entwined with sexuality, especially homosexuality. Thus, fundamental assumptions about what “counts” as a scientific fact cannot be understood without explicit acknowledgement of homosexuality, deviance, and other associated cultural meanings embedded within conceptualizations of risk. As Steven Epstein (1996) eloquently details:

Faced with a “gay disease,” epidemiologists immediately fastened upon the most sensational markers of homosexual difference, trumpeting the cases of men with histories of thousands of sexual partners, while ignoring the cases, also reported by clinicians from the very beginning, of gay men who were monogamous or who engaged in relatively modest amounts of sexual experimentation. (Epstein, 1999, p. 49)

Adopting sensationalizes understandings of homosexual behavior as risky has distinctly shaped the construction of scientific populations of interest in HIV research, both historically and today (Patton, 1990; Treichler, 1987). One of the best examples is the use and reuse of the category “men who have sex with men”. MSM – while initially created by activists for the purpose of drawing attention to a group in need of HIV prevention messaging and outreach (Aggleton & Parker, 2015) – was quickly adopted and modified in medical research. MSM was reconfigured by epidemiologists to detail patterns of HIV risk according to sexual practices that were defined by biological anatomy. As the epidemic evolved, so did the category of MSM and embedded meanings of risk. Indeed, the global dissemination of MSM and 30 years of use has shown the power of this biomedical category in shaping sexual subjectivities and lived experiences for people and communities understood to be at-risk for HIV (Boellstroff, 2011; Lorway & Khan,

2014; Thomann, 2016; Young & Meyer, 2005).

Tensions and challenges surrounding the intersection between risk and sexuality and gender-based category construction in HIV public health is not a new phenomenon, but rather an evolving one. Concurrent with the struggles of identity politics and the use of “MSM” in the late 1980s and early 1990s, “transgender” also emerged as an identifiable category during the early years of the AIDS crisis (Stryker, 2009; Valentine, 2007). Though scholars have researched the history of “transsexuality” (and other linguistic approximations for gender variance) more than 50 years prior to the advent of HIV and AIDS (Meyerowitz, 2009), the overlap and conflict between HIV, MSM, and current understandings of “transgender” as a category have been largely overlooked.

Rooted in biological essentialism, the majority of epidemiologic research assessing HIV risk among MSM has folded transgender women and other gender fluid populations into this category. However, through the work of critical scholarship and transgender activism within the past decade,⁴ the conceptual and methodological conflation of MSM and transgender women in medical research and health policy is decreasing. For example, the Institute of Medicine’s Report on LGBT Health (Institute of Medicine, 2011) and the World Health Organization’s HIV guidelines for key populations (World Health Organization, 2014) are among a growing number of recent scientific publications calling for categorical distinctions between these populations. Yet the reality of acting on these recommendations in medical research, health policy, and public health practice across varying global contexts is far from easy and full of contradictions.

⁴ For further information, see Valentine’s seminal text, *Imagining Transgender: An Ethnography of a Category*, which describes the emergence, power, and failures of transgender as a category (Valentine 2007). Importantly, this work shows the politics behind the normalization and institutionalization of the category “transgender” as a necessary fiction to promote collective identity and advocate for needed resources within legislative and social service contexts. Valentine depicts “transgender” as a site of power in which knowledge is actively being created, and that formalizes boundaries around inclusion and exclusion.

This study illustrates one such double bind. On the one hand, visibility is needed to advocate for the health needs and rights of transgender people. For example, advocacy groups such as the Global Forum on MSM & HIV (MSMGF) and the International Reference Group on Transgender Women and HIV/AIDS (IRGT) have utilized epidemiology detailing the risk profile of transgender women to advocate for treatment and prevention access, while fully understanding the limitations of the categories themselves. Advocacy groups in Peru, such as Red Trans Peru, Alma Chalaca, and Sociedad FTM (one of the first transmasculine activist organizations in Lima) have also used this tactic. Yet this type of visibility comes at a cost, as understandings of gender fluidity are filtered through risk-based epidemiology that perpetuates the continual conflation of gender and sexual diversity with HIV risk (Singer, 2015; Thompson & King, 2015).

Scholars have importantly highlighted that the creation of risky populations, surveillance of risk, and treatment of risk have direct economic gains (Birch & Tyfield, 2012; Cooper & Waldby, 2014; Rajan, 2006). As historian Jeremy Greene argues (2007), clinical epidemiology – which identifies factors associated with risk (i.e., risk-factor epidemiology) – developed in tandem with the creation not only of “at-risk” patients but also with the profit-generating practice of preemptive treatment (Greene, 2007). This is particularly evident in the case of HIV and AIDS. Yet, until recently, the same epidemiologic practices that are making risk profitable were in the past those that fueled business of HIV treatment, including the research, development, and testing of drug regimens (Crane, 2013; Nguyen, 2010; Peterson, 2014).

In the 1980s and early 1990s, the notion of prevention broadly dominated efforts to combat HIV, since effective treatment did not yet exist. As partially effective treatment became available in the early to mid-1990s, a debate about prevention versus treatment defined the

remainder of the decade (Parker, 2000). And while conversations about prevention in addition to treatment have circulated throughout the HIV epidemic,⁵ since 2000, the strategy has shifted from treatment, to treatment as prevention, to the current emphasis on prevention *as* treatment (Nguyen, Bajos, Dubois-Arber, O'Malley, & Pirkle, 2011a). This development can be traced in several ways. For example, the designation of “most at-risk” appeared most visibly in the HIV science lexicon in and around 2010. As six well-regarded HIV scientists argued in the *Journal of Acquired Infectious Diseases*, previous at-risk categories were repackaged based on prevention, using the moniker of “most at-risk populations” or “MARPs”:

Various defined, “MARPs” has referred not only to such key groups as SW [sex workers], MSM, and IDU [injection drug users], but also to truckers, prisoners, soldiers, internally displaced people, refugees, and orphans and vulnerable children. For clarity and simplicity here, we focus on SW, MSM, and IDU. However defined, what is shared by MARPs nearly universally is high vulnerability to HIV infection and low access to HIV services. (Beyrer et al., 2011, p. 1)

The authors note that “most-at-risk populations, or MARPs, have likely always been an important part of the global HIV burden” (Beyrer et al., 2011, p. 2). However, what is new about adopting MARPs as a category is that it unites the most highly stigmatized and marginalized populations affected by the epidemic, while still providing the flexibility to stratify sub-populations considered to be at-risk (e.g., MSM, sex workers, etc.). Indeed, MARPs is just one example of the strategic use of gender and sexuality-based categories to expand the HIV industry’s potential markets.

Furthermore, as Nancy Padian and colleagues highlight in their article in the top medical journal, *The Lancet*, “We have entered a new era in HIV prevention whereby priorities have

⁵ The line between the use of therapeutic drugs to *prevent* and not only *treat* HIV became blurred with the advent of ACTG 076. ACTG 076 was a clinical trial testing drug regimens of short-course AZT among pregnant women to assess effectiveness in preventing the transmission of HIV to unborn children (Angell, 1997; Bayer, 1998; Burgess & Pretorius, 2012; Lurie & Wolfe, 1997).

expanded from biomedical discovery to include implementation, effectiveness, and the effect of combination prevention” (Padian et al., 2011, p. 269). However, this shift to include prevention as a form of treatment has created particular forms of value-making. In the words of Joseph Dumit,

When the risk of a disease comes to be seen as a disease in itself, then clinical trials can be designed to test lifelong treatments for that risk factor, and this is a vastly bigger market. Treatments that reduce risk ostensibly could be indicated for all of us since we are all at risk for most diseases. (Dumit, 2012, p. 7)

One of the motivating factors for risk rebranding in the 4th decade of HIV is a new use, a new modality, of a drug previously used for treatment that has been moved into prevention and, thus has created the potential for long-term use. This drug is PrEP, a combination of HIV treatment drugs that therapeutically *prevents* disease acquisition. Indeed, available and emerging variations of PrEP represent an enormous profit incentive, for academic researchers, who are paid to carry out the research with public funds, and Big Pharma alike. With this in mind, the advent of PrEP trials post-2010, are in part, what make Peru a salient case study to illustrate the ways multiple dimensions of value have spurred the growing HIV prevention industry, not only among people deemed at-risk for HIV, but now those *most* at-risk.

A particularly queer form of therapeutic citizenship

As a second key contribution, my research carves out a new intellectual space through which to understand the profound transformations that HIV has had in destabilizing the social contract between the state and certain citizens. To achieve this, I am in conversation with the robust social science scholarship assessing governance, citizenship, and responsibility for health. Much of this work is guided by Michel Foucault’s theory of biopolitics and subsequent scholarly interpretations. For Foucault, biopower describes the processes of having and exerting power

over bodies; in his words, “An explosion of numerous and diverse techniques for achieving the subjugation of bodies and the control of populations” (Foucault, 1990, p. 141). Contemporary theorizations of biopolitics have problematized to varying degrees the centrality of the state and/or nationalized populations (Rabinow & Rose, 2006; Raman & Tutton, 2009). HIV is a transnational phenomenon falling outside the boundaries of any one state entity, and so a direct application of biopolitics to HIV science is problematic. Nonetheless, I take inspiration from these scholars in considering how biopolitical processes operating through global governance systems shape HIV science and the research industry in important ways (Parker, 2000).

While HIV has always extended beyond geopolitical borders, this reach has become particularly evident since 2000, due to the growth of multinational political actors and the proliferation of funding for HIV and AIDS-related programming (Parker, 2002). This period in the third decade of the epidemic is frequently referenced as “HIV scale-up” (Kenworthy & Parker, 2014). In fact, in the 3rd decade and throughout the 4th, bilateral and multilateral organizations have provided an estimated \$562.6 billion USD globally to fight HIV and AIDS (Global Burden of Disease Helath Financing Collaborator Network, 2018). This unprecedented expenditure for a singular health outcome underscores the support and political importance behind these initiatives. Additionally, this rise in funding was met with a rise in multilateral agencies. For example, in 2001, the historic United Nations General Assembly Special Session (UNGASS) on AIDS made a call for and endorsed a global funding mechanism to fight AIDS alongside tuberculosis and malaria through the creation of the Global Fund (Kallings, 2008; Kenworthy & Parker, 2014).⁶

⁶ By 2010, UNGASS global targets included to reduce HIV prevalence by 25% globally among people aged 15–24, to ensure that at least 95% of people aged 15–24 have access to information “to reduce their vulnerability to HIV infection,” and to reduce the proportion of infants infected with HIV by 50%, particularly by increasing access to

To give an example of the magnitude of this funding, according to anthropologist and physician Vinh-Kim Nguyen, in some African countries, PEPFAR and the Global Fund have funds exceeding the entire national health budget at their combined disposal (Nguyen, 2009). Indeed, HIV has distinctly shaped modalities of governance, bringing to the fore questions of citizenship, health, and the centrality of the state versus other key actors linked to the epidemic (i.e., NGOs, CBOs). To explore how HIV has shifted notions of power, sovereignty, and belonging, I lean on scholars who assess biopolitics at the intersections of global public health (Crane, 2013; Geissler, 2015; Nguyen, 2010; Prince & Marsland, 2013).

Ruth Prince and Rebecca Marsland (2014) argue that central to the field of global public health are “conceptions of the public sphere, the public good, and the public itself as an imagined collective” (Prince & Marsland, 2013, p. 34). Objectives to improve people’s lives and wellbeing are embedded in notions of “public good,” and often animate public health efforts. Yet these efforts have profoundly shifted the social contract between the state and its citizens, revising where the responsibility for equitable health interventions lies, as these efforts are short-lived and frequently further destabilize people and state-sponsored public health systems in their wake (Crane, 2013; Geissler, 2015; Kenworthy, 2017; Nguyen, 2009; 2010).

For example, in his ethnography of the impacts of global HIV treatment efforts in Francophone West Africa, Nguyen argues that international funding and its implementation to the local HIV and AIDS epidemic has “unwittingly sorted those who should live from those who could go without treatment” (Nguyen, 2010, p. 6). Nguyen uses the term “therapeutic citizenship” to highlight that this represents a new site upon which claims for resources based on the relationships between a biological condition and the global biomedical HIV industry can be

antiretroviral therapy. These targets further specify the general UN Millennium Goal to halt and begin to reverse the spread of HIV/AIDS by 2015 (Kallings, 2008).

made. Reaching beyond state-level governance, therapeutic citizenship also applies to the broader political economy of health scholarship to question the impacts of international clinical research trials, pharmaceutical companies' pricing of medication, and access to life-saving medication in local contexts of resource scarcity (Biehl & Petryna, 2013; Busfield, 2016; Crane, 2013; Dumit, 2012; Nguyen, 2010; Petryna, 2007).

Likewise, Robert Lorway analyzes the Gates Foundation-funded HIV initiative to show how enumerative techniques embedded within global health HIV interventions rewrite the social contract between citizens and the state. Coining the term "evidentiary sovereignty," Lorway argues, "The artifacts of evidence production themselves become the very site of politicization and struggle for communities seeking to improve the health, safety, and wellbeing of their members" (Lorway, 2016b, p. 191). Particularly applicable to my study, Lorway underscores the ways in which global health funding brings with it demands of doing public health in certain ways that undermine local ownership and community control in the response to HIV, such as systems of classifying certain bodies and sexual identities.

Lorway's argument is in direct conversation with scholars who emphasize the contemporary prominence of numerical indicators in the production of global health knowledge, and the unexpected ways that these data become embedded and embodied in the practices of *doing* health (Adams, 2016; Biruk, 2018; Fan & Uretsky, 2016; Lorway, 2016b). As Vinceanne Adams details, "Quantitative metrics that make use of evidence-based statistical measures, experimental research platforms, and cost-effectiveness rubrics" (Adams, 2016, p. 1) rule global public health politics today. My study shows that quantitative data takes on new weight in contemporary HIV politics, enumerating and further detailing risk, and fostering new subjectivities among people classified as target populations through experimental forms of

biomedical HIV prevention and care.

Peru is not a failing state, unlike the majority of examples in the literature that focus on the impact of HIV global public health efforts in the context of under-developed or destabilized health systems, nor has it been exposed to large sums of humanitarian or AIDS relief funding (i.e., Gates Foundation). Rather, flows of international HIV and AIDS funding to Peru have been narrowly focused on research, specifically research targeting those deemed most at-risk (versus the general population, as in the African context). Because understandings of risk categories within such research explicitly implicate queer people, my study analyzes the emergence of a particularly queer form of therapeutic citizenship. The HIV prevention paradigm shaping the 4th decade of the epidemic has made the health and wellbeing of queer bodies the newest object of scientific knowledge and regulation. What is quite astounding is that precisely two of the most highly stigmatized and marginalized populations affected by the epidemic – populations that have fought for three decades for adequate recognition – have suddenly become so central to HIV prevention science. In this context, the magnitude of the shift combined with new notions of value raise uneasy questions about the ethics of making people of diverse genders and sexualities the next biological target in the fight against HIV and AIDS.

Contradictions of queer visibility

Finally, this study sheds new light on the explosion of scientific knowledge about certain queer bodies linked to the emergence of a prevention paradigm in the 4th decade of the HIV epidemic. In particular, the development of drug technologies to prevent HIV has fueled a marketplace targeting not just groups considered to be at-risk for HIV, but those believed to be *most* at-risk. Yet the practices and performances by which HIV prevention science is

adjudicated, valued, and held accountable (or not) are historically and culturally specific. Thus, this dissertation is also in conversation with the increased visibility of sexual rights in the 21st century, and the imaginary of LGBTQ inclusion within progressive politics. In the chapters that follow, the idea of imagined queer bodies is important in two ways. First, it deepens our understanding of how identity and subjectivity are shaped, enacted, and embodied through HIV biomedical prevention science. And, secondly, it demonstrates that the focus on MSM and transgender as experimental subjects imbues contemporary HIV science with progressive imaginings.

Following Benedict Anderson (1983), Arjun Appadurai (1996), Charles Taylor (2004), and others, I adopt the analytic of imaginaries to think about imagination not solely as fantasy, but as the social processes that animate common understandings, common practices, and understood legitimacy of the social world (Anderson, 1983; Appadurai, 1996; Taylor, 2004).⁷ Additionally, I engage the concepts of technoscientific imaginaries (Marcus, 1995) and sociotechnical imaginaries (Jasanoff & Kim, 2015), which theorize the role of science, technology, and society in creating a vision for the future that informs social and political decision making. Technoscientific and sociotechnical imaginaries, though similar, are distinct in that they work at different levels. While technoscientific imaginaries is concerned with “the context of the imagination is the scientific workplace, and [how] imagination’s aims and achievements are tied to forms of scientific production” (Jasanoff, 2015, p. 11), sociotechnical imaginaries can be understood as a larger, more ambitious theoretical intervention. Its aims are:

To investigate how, through the imaginative work of varied social actors, science and technology become enmeshed in performing and producing diverse visions of the collective good, at expanding scales of governance from communities to nation-states to the planet. (Jasanoff, 2015, p. 11)

⁷ For more on this scholarship, see Sheila Jasanoff’s key summary on “imagination as social practice” (Jasanoff & Kim, 2015).

Together, these concepts are useful for understanding the creation of MSM and transgender women as the populations most at-risk, and the active “buying-in” process that multiple actors engage in to conduct offshore clinical research – a process that is extremely work intensive and, at times, exploitative. Marcus is particularly helpful for thinking through the rise of expert networks and practices of expertise that fuel forms of scientific knowledge production, such as credentials, authorship, and claiming ownership of data (see Chapter 2). Yet technoscientific imaginaries alone fail to account for globalization and the power embedded within the postcolonial imagination. Sociotechnical imaginaries allow for an explicit analysis of how the strategic growth of transnational pathways between the US and Peru established Peru as an offshore research site and ideal marketplace in which to test HIV biomedical preventions strategies on people categorized as MSM and transgender women.

Advancing this scholarship, I argue for the unique and powerful role of global public health interventions. The rise of offshored HIV clinical trials focused on people of diverse genders and sexualities shapes the collective social imaginaries of who these people are. Additionally, visibility for certain queer bodies within this research, namely those people categorized as MSM and transgender women, is linked with progressive politics and associated understanding of sexual rights. Undeniably, global public health and clinical trials fall under the rubric of sociotechnical imaginaries as theorized by Jasanoff and Kim, yet there are important and neglected dimensions in assessing imaginings related to gender and sexually diverse communities.

Indeed, one of the main critiques of sociotechnical imaginaries is that, when applied as a theoretical lens, “it can become limited to descriptive cultural analysis rather than including the

full interplay of actors, social structures, and institutions in the explanation of sociotechnical change” (Sovacool & Hess, 2017, p. 719). As such, this study brings queer theory into conversation with sociotechnical imaginaries to highlight not only the performances and practices embedded within biomedical research, but also to understand this industry as a unique social structure that expands a scientific vision of sexual activity, sexual identity, and gender identity.

Today, the categories MSM and transgender women are deployed and utilized in HIV science in ways that move beyond both biomedical arenas and geographic boundaries, and intersect with the most intimate aspects of daily life. To more fully understand this, it is useful to draw on Ian Hacking’s idea of “making people up” (Hacking, 2006), which signals the ways in which people are categorized by authorities and how these categories in turn affect the subjectivity and lives of the people so classified. In the chapters that follow, I illustrate the ways in which being classified (or classifying oneself) within the biomedical categories MSM and transgender in the context of participation in HIV research also affects understandings of health, wellbeing, sexuality, and gender. While Peruvians have contested and adapted these imported biomedical categories, the reciprocal relationship between classificatory practices of HIV science and the people who are classified not only as MSM and transgender but also as experimental subjects, nonetheless deeply impacts people’s identities and subjectivities.

Martin Holt builds on Hacking by considering how scientific and public health imaginaries of gay men interact with broader gay collective identities. In the context of an annual and large-scale Australian HIV behavioral surveillance study, Holt draws attention to the ways HIV research practices, such as study surveys, “inadvertently affect gay men’s perceptions of themselves and their practices” (Holt, 2013, p. 413). He argues that by including questions and

multiple choice responses that perpetuate imaginaries of gay promiscuity, these research instruments may “reinforce some of the behaviors it [public health] investigates” (Holt, 2013, p. 413).

To illustrate this point, Holt shows that while 80% of gay men surveyed responded that they always used a condom, the survey nonetheless asked variations of this question six times. Thus, further questions regarding unprotected sex were not only irrelevant but also stigmatizing. Moreover, in many cases, these multiple iterations of the same question collected data that went well beyond HIV prevention efforts, pointing to broader imaginings of gay deviance and promiscuity. For example, the questions, “I fucked him without a condom but pulled out before I came,” and “I fucked him without a condom and came inside [him],” are not linked to HIV transmission (Holt, 2013, p. 413). Further, details about ejaculation are beyond the scope of the questions’ intent, and only serve to reinforce stereotypes about gay men. The inclusion of such questions also demonstrates ways in which this imaginary influences research design.

My observations of HIV prevention science in Peru similarly underscore how imaginaries of MSM and transgender women shape the construction of research practices and analyses of the derived data. For example, not all people who could potentially be classified as MSM and/or transgender are recruited into these studies. Rather, eligibility is restricted to MSM and/transgender women who additionally reported elevated risk factors, such as recent unprotected sex. I argue that such restrictions inform these categories and reify particular imaginaries of gender and sexual diversity in HIV prevention science that aim to produce knowledge about queer bodies and risk. As another example, in Peru, available public health literature contends that transgender women are the group most affected by HIV, with a prevalence of 30% compared to 0.23% of the general population (Silva-Santisteban et al., 2012).

However, the “general population” data is from a random sample, but the data from “transgender women” reflects only a subset of this community. Transgender women with stable partners are not included in these data, thus defining a primary at-risk category as inherently promiscuous.

HIV science is only one of several influential forces on the global stage that has historically shaped and continues to shape queer identities, articulations of queer communities’ needs, and their demands for rights. This dissertation assesses the contemporary politics of classifying MSM and transgender within the HIV prevention industry, but imaginings of MSM and transgender women certainly predate the current use of these categories in HIV science. During the first decade of the 21st century, queer identities have developed in critical conjunction with a growing global focus on the politics of sexual rights that is in many ways entangled with capitalism (Corrêa et al., 2008; Graham & Padilla, 2014; Lind, 2009; Parker, 2012; Parker et al., 2004; Petchesky, 2000). My thinking about queer identities and categories is particularly indebted to this scholarship, as it has illustrated that although expanding visibility and recognition of diverse sexual communities has created new spaces to debate and claim human rights, these spaces also fall prey to preexisting agendas that discipline what types of queer bodies are made visible. For example, Amy Lind (2010), working at the intersection of the global development industry and queer politics, states:

The liberatory potential of “queering development” is complicated by neoliberal politics, including how some development institutions and nation-states are increasingly embracing gay rights through a neoliberal lens, whereas others continue to view sexual/gender deviance as an added threat to what they view as the already-existing imposition of (Western and/or imperialist) neoliberal agendas. (Lind, 2010, p. 12)

Central to what Lind refers to as “embracing gay rights through a neoliberal agenda” is the increasingly globalized capitalist nature of societies and how queer subjects fit in within this system (Lind, 2010, p. 12). For example, in the context of the post-2000s global movement for

LGBTQ rights, scholars have drawn attention to political strategies among states, institutions, businesses, etc. that promote an image of LGBTQ acceptance or allyship in order to be perceived as progressive and tolerant. Terms such as “pinkwashing” and “rainbow capitalism” have emerged to define this type of cause marketing. One illustrative example of pinkwashing is Benjamin Netanyahu’s appropriation of LGBTQ rights to “market [Israel] as a human rights leader based on its stances on same-sex marriage and LGBT military service. Israel has explicitly worked with marketing experts to ‘rebrand’ itself, trying to overcome its international reputation as a brutal occupying force” (Spade, 2013, p. 87).

In addition to understanding state actors’ use of LGBTQ rights as part of a political enterprise, the visibility of queer communities in the 21st century is inextricably linked to capitalism. As a point of departure for thinking about this historically, John D’Emilio argues that “lesbian and gay identity and communities are... the result of a process of capitalist development that has spanned many generations” (D’Emilio, 1983, p. 139). Indeed, many pioneering scholars have further argued that the explosion of visibility and possibility related to sexual life is a defining condition of late-modern capitalism (Foucault, 1990; Weeks, 1985). The HIV epidemic has created new social, cultural, political, and economic possibilities to both destabilize and provide new reconfigurations of the relationship between global queer identities and capital in ways that are both related to these historical developments and still being determined today (Altman, 2002; Castells, 2004; Parker, 1999).

In addition, the power of queer communities, both north and south of the equator, has been instrumental in advocating for health and sexual rights in the contemporary world. This has again been particularly evident regarding HIV and AIDS. The epidemic has profoundly shaped activism for sexual rights, and, in turn, this social and political work has deeply affected HIV

science (Colvin, 2014; Epstein, 1999; 2009; Parker, 1999; Seckinelgin, 2009). Indeed, queer advocacy around sexual rights developed in tandem with AIDS activism from the beginning of the epidemic and into the early 21st century – an entanglement that helped prioritize research related to MSM and transgender populations in responding to HIV (Altman, 1997; Colvin, 2014; Epstein, 1999; 2009; Hanssmann, 2010; Lorway, 2016a; Monro, 2013; Seckinelgin, 2009; Thompson & King, 2015). It is thus critical to recognize these three forces that have helped shape how queer bodies are imagined: the growing global focus on sexual rights during the first decade of the 21st century, the politics of LGBTQ rights in relation to capitalism, and the interactions of both with HIV science. This larger context is useful for situating the contradictions and challenges we see today in HIV biomedical prevention science.

It may seem surprising that I pay scant attention to activism in my analysis, especially considering this history. My intention is not to imply that Peruvians have failed to contest or have passively accepted processes of scientific classification, nor that there has not been local advocacy for needed AIDS-related care (Cueto, 2001; see Frasca, 2005; P. Goicochea, 2007). Rather, the absence of activism in my narrative points to a recent shift. Four decades into the HIV epidemic, the people who make up the categories of MSM and transgender have, in a sense, become legitimated. Visibility for people of diverse genders and sexualities is no longer the battleground, even though only certain people of diverse gender and sexualities are seen through HIV prevention efforts. While other contemporary actors are fighting for transgender visibility (i.e., transgender identity legislation) and/or gay rights (i.e., same-sex marriage, immigration rights), inclusion of diverse queer communities within HIV science now seems to be a non-issue. Sexual orientation, and now gender identity, have become scientifically legitimate, albeit separate, research variables (Epstein, 2009). Queer people are being counted.

However, I argue that there is a significant paradox within this contemporary focus on gender and sexual diversity in HIV prevention science: it gives the impression that progressive health politics are being enacted, while obscuring and absolving ongoing forms of exploitation and unequal gains embedded within this research system. Indeed, HIV prevention research promotes an image of serving the LGBTQ community as a whole, but actually focuses almost exclusively on those perceived to be the *most* vulnerable, those *most* at-risk. Structural inequalities like social marginalization and economic instability increase their vulnerability to HIV, yet these are the very same factors that enable the biomedical research enterprise to exploit and control people of diverse genders and sexualities as research subjects.

Research Methods

Ethnographic epidemiologist

I approach the construction and use of sex and gender categories in HIV science as an ethnographic epidemiologist. Building on a Latin American tradition of “epidemiology without numbers” (Ayers, 1994; de Almeida Filho, 1992; Parker & Camargo, 2000) – which draws attention to the often invisible sociocultural politics of vital statistics measurement and calculations – my methodological approach is intentionally political and reflective. As noted previously, I worked in Peru on US-funded HIV biomedical prevention research focused on people categorized as MSM and transgender prior to and throughout graduate school. Embedded in a team of physicians, epidemiologists, and study staff, I became deeply engaged in the implementation of day-to-day clinical trials. In the nine years since beginning this work, I have had multiple roles that have offered me a longitudinal, 360-degree perspective of the tangible and intangible work necessary to do research. As a research assistant, then analyst, and

more recently holding a leadership position overseeing these studies, I have continually grappled with the tension between the desire to produce scientific knowledge and the challenges, and at times harm, created for the people who make these studies possible.

Given the intertwined relationship between my professional trajectory and the ethnographic inquiry that became the focus of this study, it is difficult to determine when my dissertation research began. But starting in February 2017, I embarked upon two years of formal ethnographic research, which included participant observation of clinical trials, in-depth interviews with scientists and people who participated as human subjects, and analyses of scientific publications and protocols. Below is a brief overview of my research approach and methods for this study. Detailed descriptions, including tables of summary characteristics, for the three HIV prevention studies observed (Appendix A) and of the people I interviewed one-on-one and through community discussions/focus groups (Appendix B) are available in appendices.

Observations

During my fieldwork, I actively observed three ongoing HIV prevention biomedical studies. Two exclusively focused on transgender women, and the third, although focused on MSM, also recruited transgender women. See Appendix A for further information about the central aims and research design of these studies. My observations occurred in a variety of settings, including but not limited to four separate clinics, numerous training sessions, and recruitments events, all of which encompassed study participants, providers, study staff, and, research scientists. I conducted observations to track the different meanings embedded within doing research on and being classified as “MSM” and/or “transgender” research participants.

As a member of the leadership team for these studies, I was well positioned to observe the politics and behind-the-scenes practices necessary to make transnational clinical research work. This involved participation in weekly conference calls, in-person meetings, and email correspondence. Observing research scientists presented opportunities to further understand the rationale behind how studies are designed and how successes are assessed and valued. I compiled descriptive field notes throughout my observations, which were particularly useful when observing my colleagues and mentors, as I sought to be reflexive about my unique position in these studies as both an insider and an outsider.

In addition, I paid careful attention to the tensions that emerged between sex and gender categories as used in HIV science and how they were understood, contested, and at times resisted in daily research practices. This tension was often evident not with words, but with visual responses and sounds, such as groans, awkward laughs, and sighs. For example, during a street-based recruitment session, a fieldworker approached two potential research participants and asked, “Are you interested in participating in a research study for trans women (*mujeres trans*)?” One potential participant rolled her eyes, laughed, and addressed her response to the fieldworker and her friend: “Me, yes, I’m trans. But not her, she’s a *travesti*.”

Observations like this one were crucial to capture the playfulness that emerges in group settings, and the strategic use of categories that is not as readily conveyed in interviews. This example also highlights the hierarchical distinction between *trans* and *travesti* in daily life, versus what can be accurately captured through standardized biomedical terminology and accompanying practices. In this interaction, we see several things occurring at once. One is a push back on the recruiters’ assumption that both are trans. The second is the use of *travesti* as a slight dig, teasing among friends, which I noticed through visual cues. Finally, by saying that she is

trans, she implies that she can participate in the trial, while her friend, as a *travesti* (a term closely associated with street-based sex work and fewer economic resources in the Peruvian context), cannot. Although she was making a joke, she also identified important differences that inform a hierarchy of terms used to denote gender diversity. Yet in clinical research practice, both individuals were recruited as “transwomen,” thus flattening these nuances.

Semi-structured interviews and community discussions/focus groups

Between February 2017 and February 2019, I conducted a total of 110 in-depth semi-structured interviews: 33 with research scientists, 17 with study staff (including clinicians and peer-recruiters), and 52 with people who were current participants or had previously participated as human subjects in HIV prevention research. I also had the opportunity to interview three US National Institutes of Health personnel that currently or previously oversaw US-funded projects in Peru, and one past employee at Gilead who had facilitated the donation of Truvada for iPrExm and four US medical students conducting a global health fellowship in Lima, Peru. Additionally, I conducted 10 community discussions/focus groups, which included 83 participants. Depending on participants’ preferences, interviews were conducted either in English or Spanish, and in person or via telephone or video chat, and all conversations were digitally audio recorded in order to capture participants’ exact responses. All community discussions/focus groups were conducted in Spanish and in person. Interviews lasted approximately an hour and a half; however, follow-up conversations tended to be shorter, around thirty to forty-five minutes.

My interviews with research scientists (both American [n=16] and Peruvian [n=17]) provided insight into the historical linkages between US and Peruvian investigators, and the strategic processes and politics involved in doing transnational research. By analyzing scientists’

descriptions of expertise on HIV prevention research focused on people of diverse genders and sexualities, I gained understanding of the varied ways that such expertise is defined, produced, and maintained. Furthermore, I asked key questions about training pathways and metrics for career advancement to better ascertain meanings of value. My conversations with NIH program officers and the former Gilead employee focused on the rationale for funding HIV prevention science in Peru, and administrative processes to support this research.

Conversations with study staff allowed me to detail the processes, skills, and tacit knowledge required to implement research, and, importantly, highlighted the challenges of aligning local gender and sexual diversity with the biomedical expectations within “MSM” and “transgender women.” For example, in describing her experience assisting a participant fill out a survey, a nurse stated, “The participant told me she was trans and heterosexual. But only has sex with other men. So, shouldn’t I mark homosexual on the survey?” Such misunderstandings – and confusions related to overlap between gender identity, sexuality, desire, and intimate practices – were frequent, and often became the focal point of study staff’s frustration and confusion regarding the difficulty of producing biomedical data.

Among Peruvians of diverse gender and sexual identities, I interviewed 37 people who were currently engaged in HIV prevention research and 15 who had previously participated. Through the support of study staff and peer-recruiters with whom I had previous relationships, I conducted interview recruitment via convenience sampling methods. The identity terms participants used to describe themselves, whether gay, trans, *travesti*, etc., are the terms I use in this project. In total, I interviewed 22 people who self-identified or were categorized as MSM, and 30 people who self-identified or were categorized as transgender women. These interviews took place in a range of settings, including people’s homes, street corners, private spaces in

clinics, activist organizations, and cars. Conversations explored the lived experiences of participating in HIV prevention science and its impact on the care they received. Also central were the meanings of the categories MSM and/or transgender, tensions that accompanied the use and application of these categories, and the influence of HIV science in constructing these categories and/or policing the boundaries of membership within them.

Please note that in order to protect the anonymity of informants, pseudonyms have been used throughout and some biographical data has been altered or withheld in order to ensure the privacy of informants. References to social class, sexuality, and/or gender identity are based on the informants' own classification. The only exceptions are quotes from Dr. Jorge Sánchez, primarily in Chapter 2, that detail the history of US funded training pathways from Peruvian investigators. In these cases, I double checked each quote with him to confirm its accuracy and his willingness to be specifically named as a key source in the dissemination of these data.

Document analysis

Document analysis focused on scientific publications, protocols, recruitment media (i.e., Facebook marketing, flyers, etc.), and funding reports linked to the three HIV prevention trials I actively observed. Assessing various documents, such as grant applications, IRB applications and consent forms, and regulatory documentation for PrEP importation, as well as peer-reviewed literature, revealed insights about how most at-risk populations were being conceived to support biomedical approaches to health. This aspect of the inquiry closely examined the ways that “value” was described, both in terms of the importance of the scientific knowledge produced through these studies *and* the need for more biomedical research on people categorized as MSM and transgender women.

Additionally, closely analyzing Peruvian Ministry of Health guidelines and national strategic plans since 2000, I traced multiple trajectories in the development, regulation, and implementation of HIV prevention and care for gender and sexually diverse Peruvians. First, I documented the separation between the categories of MSM and transgender women, as two distinct populations considered most at-risk within the Peruvian HIV epidemic. And second, I focused on various configurations of gender and sexually diverse people as “risky” or “most-at risk” for HIV. In particular, the Peruvian National Guidelines for Transgender Health⁸ (Peruvian Ministry of Health, 2016) emerged as central to my document analysis. This policy guideline was based on a protocol for an HIV prevention and care biomedical study that provided cross-sex hormones to transgender women to improve retention in HIV services (i.e., incentives to engage routinely in HIV services) (see Appendix A for further details). While initial drafts of this document circulated in 2016, it was not approved until 2017, and finally implemented in 2019. These diverse documents enabled me to map the ways that scientific classifications of MSM and transgender women are strategic (and often contradictory) sites in which to enact HIV industry agendas.

Dissertation Structure

This dissertation’s title, “HIV Prevention Science and the Business of Gender and Sexual Diversity,” captures the deep entanglement between HIV prevention efforts and capitalism in contemporary scientific and public health agendas targeting populations deemed most at-risk – namely, people categorized as MSM and transgender women. While a significant body of literature now traces the infiltration of economic logics into health research, I argue that the

⁸ Full document is available online here: ftp://ftp2.minsa.gob.pe/normaslegales/2016/RM_N%C2%B0_980-2016-MINSA.pdf

contemporary HIV research industry's focus on gender and sexual identities is a newly imagined and thus strategic site for extractive biomedical prevention practices. Consequently, this study is also a lens into the contradictions of visibility for queer communities, and engages with ongoing debates around pinkwashing and rainbow capitalism. Each chapter centers on the double bind of opportunities versus opportunity costs in this political economy of HIV prevention science to illustrate the difficult ethical balance among human subject experimentation, innovation, and access to, albeit temporary, HIV services.

Chapter 2, "Contours of the Field," tracks the historical entanglement between the United States and Peru that primed Peru to become a hotbed of HIV research, arguing that the region was intentionally structured as an offshore research site (i.e., *visión gringa*). The direct importation of risk categories, US-trained experts, and the creation of institutions capable of doing science in ways required by US funders led Peru to become an ideal biomedical research marketplace to fulfill global North goals. Indeed, considerable global North financial and social investments and the creation of HIV science training pathways, though laudable, created a system dependent upon transnational agencies and private partners' support. That the structure of Peruvian HIV prevention science exists in conjunction with the global HIV industry inadvertently diverts attention from the complex practices of *doing* global health research – practices that introduce new and reinforce pre-existing inequalities in the global South.

"Commodified Identities," Chapter 3, illuminates how the use of MSM and transgender women as biomedical categories are not simply systems of classification based on gender and sexuality. They also serve as surveillance technologies, powerful tools through which multiple actors can not only collect data (commodities), but also claim and leverage expertise (assets) about certain bodies and identities in order to obtain funding and publications, and expand their

dominance in the field of HIV science. Linking these practices to the broader HIV political economy, this chapter argues that it is the promise of future research that, combined with understandings of risk, further fuels the value of data extraction among gender and sexually diverse communities in HIV prevention research.

Chapter 4, “The Research Enterprise,” details the micro-economies that emerge at each step of the research process to show the active practices and performances that commodify people of diverse genders and sexualities. These dynamic methods of *doing* research divert attention from underlying processes that transform people into participants, laborers, and, finally, dehumanized data. While those at the top (i.e., expert scientists, funders, etc.) view clinical research as both voluntary and seamless, this chapter demonstrates that this far from true. It takes considerable effort and creative strategizing to deliver a final product, and not everyone benefits equally. By exploring the governing logics and performances of doing HIV science, I show how the relationships between people and organizations are transformed into transactions at every stage of the research process. In doing so, I complicate common characterizations of research participants as volunteers acting upon free will, and draw attention to the significant amount of unrecognized labor necessary to conduct this research, particularly among those at the lower levels of the institutional scientific hierarchy: peer recruiters and participants.

Finally, the Conclusion, problematizes contemporary imaginings of HIV prevention science as progressive due to the inclusion and visibility of people of diverse genders and sexualities. Rather, the impacts, benefits, and value of this research are much more complex. I demonstrate that, in reality, only some Peruvians with diverse genders and sexualities (those classified as MSM and transgender women) are afforded access to front-line strategies to prevent HIV. Moreover, such access is limited to those who become human subjects in experimental

biomedical research, and it is also only temporarily available during the period of the study. While these studies are significant in advancing biomedical HIV prevention efforts, the translation of this research into policy and drug access is largely limited to the global North. The visibility of queer experimental subjects conceals this unfortunate truth and the lack of state-sponsored services for people of diverse sexualities and genders. The result is a growing pool of people in need of HIV care who serve as an exploitable research population that sustains this biomedical marketplace.

Chapter 2

Contours of the Field

“Everyone's going to Peru, and it's not because they have a huge epidemic. It's because of the research climate.”

-Robert Grant, UCSF virologist and
Principal Investigator of the iPrEx clinical
trial⁹

In 2006, the journal *Science* published an editorial highlighting Peru's curious status as “a new nexus for HIV/AIDS research” (J. Cohen, 2006). Why Peru? To answer this question, the editorial cites concentrated incidence rates among MSM in cities like Lima and Iquitos and their willingness to participate in HIV research, but also suggests that explanations usually return to two key investigators, Jorge Sánchez and Carlos Cáceres:

Sánchez and Cáceres—who, to the frustration of many, have a strained relationship—command wide respect from colleagues around the world. Sánchez was the first of some 40 Peruvian researchers who were funded by NIH's Fogarty International Center to train at the University of Washington (UW), Seattle, with King Holmes, a renowned expert on sexually transmitted diseases. Sánchez then headed Peru's national AIDS program within the Ministry of Health. When he left, he took many members of his team and started *Impacta*. His group now collaborates with both UW and Grant's lab at UCSF. Cáceres has a doctorate in public health from UC Berkeley and works closely with Thomas Coates's AIDS research team at UC Los Angeles...

Sánchez and Cáceres have a deep understanding of the communities that they are studying because they are both part of them. “I know exactly what it means to have a partner who weighs 40 kilos and you need to take him to shower because he cannot shower himself,” says Sánchez, who had a partner die of AIDS in 1990. “I cannot take my personal life out of my thinking.” Cáceres, too, says his personal links to the community shape the way he does epidemiology. “It's public health and prevention mixed with sexual rights and human rights and empowering the community,” he says. (J. Cohen 2006, p. 289)

The editorial describes Peru as an “incongruous hotbed” of research. This characterization is due

⁹ Quoted in J. Cohen 2006.

to two factors. The first is the contradiction between the amount of research conducted and the benefit of this research for the communities most impacted by HIV. The second is the interpersonal tensions at an expert-level, to which the above quote alludes. On the one hand, the article notes, the “scale of the research enterprise is remarkable given the government’s foot-dragging when it comes to offering anti-HIV drugs to people who need them” (J. Cohen, 2006, p. 489). On the other, the central (albeit contentious) role of these two scientists with ties to US institutions has created a research infrastructure in line with global strategies and sustained by international funding.

Drama among Peruvian experts has captured widespread attention and permeated global knowledge networks. In 2009, while preparing for my initial move to Lima, I remember being struck by the reaction of a US-based senior physician epidemiologist who referred the *telenovela* (i.e., a Spanish language soap opera) of Peruvian HIV research. This was not a singular occurrence. Over the next several years, as I progressed through various milestones in my public health training and disclosed my connection to Peruvian HIV research, this theme reemerged at international conferences and in conversations with fellow researchers. Interestingly, I was never asked how or why I ended up in Peru. Rather, with the inherent recognition of Peru as a hotspot for HIV research, the question that, without fail, always came was, whose “camp” did I fall into.

I quickly learned that professional affiliations marked collaborative lineages or divided experts, institutions, and, at times, research foci. My process of learning how to conduct scientific research studies (i.e., behavioral and clinical trials) seemed to depend not only on understanding methodology, but also on the social arena within which the research was conducted. Prior to moving to Peru, I was aware of the volatility of the HIV landscape, marked by changing alliances between Peruvian researchers. However, it was not until I began my own

formal public health training in the US that I saw how these divides extended beyond Peru and could be traced to US-based partnerships, bringing with them the weight of historical antecedents and funding allocations. More importantly, these schisms also seemed to influence the production of HIV knowledge and, ultimately, define Peruvian systems of HIV care affecting the most vulnerable communities.

As my career trajectory within this arena developed, I began to break away from the perception of Peru as a *telenovela* and instead became interested in the structural factors that created and maintained this research climate. Again, why Peru? Why did Peru end up being so prominent in the field of global HIV research? And, particularly among people of diverse genders and sexualities classified as most-at risk? As highlighted by the *Science* article, many think it is because of Sánchez and Cáceres—super investigators who know how to work the system. But *are* they the major players? Or are they only part of a much bigger picture?

In this chapter, I argue that the long-standing entanglement of US and Peruvian researchers and institutions has structured the production of global HIV knowledge in important ways. I demonstrate that the US government and US-based scientists primed Peru to become a “hotbed” of research, facilitating the creation of an ideal biomedical research marketplace with imported categories of risk, US-trained experts, and scientific institutions capable of complying with National Institutes of Health requirements. Furthermore, these structural aspects within the Peruvian research arena created pathways through which key actors emerged, namely those with US-based training like Sánchez and Cáceres. I contend that although these structures constrain how HIV research is conducted on the ground, they also work to empower some actors. I conclude with a discussion of iPrEX—a golden opportunity that, following 2007, propelled Peruvian HIV science and the actors within it to global prominence. Today, Peru is recognized as

a key site for a particular type of HIV biomedical prevention trials; offshore clinical research focused on people categorized as MSM and transgender women.

Visión Gringa

In 1983, the United States Navy Medical Research Institute Detachment (NAMRID)¹⁰ detected and reported the first case of AIDS in Peru (Cueto, 2001). NAMRID's distinct place in early HIV science was primarily due to circumstance; it was the only institute with the available technology to detect levels of CD4 cells in the blood (i.e., preliminary presence of HIV). NAMRID did not work in isolation, but rather collaborated with and relied on support from Peruvian physicians and physician-researchers trying to understand the emerging disease. However, these relationships and research practices fortified NAMRID's central position of power, as it became an incubator for collaborations linking Peruvian and American researchers.

In addition to applying testing technology, NAMRID and associated US scientists played a key role in determining how initial epidemiological studies of HIV defined at-risk populations. For example, sexuality and gender-based population categories (e.g., MSM, directly translated as *hombres que tienen sexo con hombres* [HSH]) were imported from the US and directly embedded into NAMRID study documents. Subsequently, these documents became the basis for future study protocols and instruments, replicated from the initial Peruvian response to the disease. Prior to the implementation of NAMRID's seminal 1985 study (McCarthy et al., 1996), Peruvian researchers contested the use of the category "MSM" because of cultural

¹⁰ NAMRID is one of five overseas US military infectious disease laboratories and the only one located in the Americas. Additionally, from 2004-2007, due to collaborations with the University of Washington, the NIH Department of Clinical Bioethics, the Peruvian National Institute of Health, the Peruvian Institutional Review Board Network, and local Peruvian universities, NAMRID became a bioethics research training hub in Latin America (Lescano et al., 2008).

understandings of sexual fluidity and the prominence of bisexuality (Frasca, 2005). But, due to the rapid implementation of NAMRID studies (and study documents), they soon abandoned these concerns. MSM and associated understandings of risk among gay and bisexual men were introduced, used, and disseminated throughout public health surveillance measures, and thus gained scientific “legitimacy” among those seeking to assess the status of the early epidemic (Cueto, 2001; Frasca, 2005).

The combination of vast technical capacity and social power established NAMRID as an institution authorized to speak for and structure the practice of *doing* HIV research. NAMRID’s importation and application of “MSM” marked this category, and the people within it, as central to the Peruvian research industry. Generating epidemiological evidence at a time when no treatment was available, on the one hand, provided data on how the epidemic was unfolding, and on the other, allowed for scientific knowledge to be produced according to a global North rubric. In the four decades since the introduction of this category and the initial understanding of “risk,” the meaning of MSM has, unsurprisingly, evolved. It was initially applied to assess “risk” behaviors of people “at-risk” for HIV acquisition and transmission. However, understandings of “risk” within HIV research have evolved, as well, as practices have grown to identify, count, and assess other emerging communities categorized as at-risk for HIV: first MSM, then cisgender sex workers (female and male), and within the past decade,¹¹ transgender women.

While Peruvian scientists and activists openly critique the limitations of the category MSM (Frasca, 2005), they maintain its “utility” for research. The result is the dominance of the

¹¹ Unlike the acronym MSM, which was created by and for the AIDS epidemic (Aggleton & Parker, 2015), terms such as transsexuality, transgender, and other linguistic synonyms for gender variance emerged more than fifty years prior to the advent of HIV and AIDS (Meyerowitz, 2009). Nonetheless, the AIDS epidemic—namely, the prominence of epidemiologic research on the incidence and prevalence of infection among “MSM”—has included transgender and other gender variant populations (e.g., those assigned male at birth who report sexual experiences with and attractions to others assigned male sex at birth, regardless of gender identity or presentation) in the category.

term across study design, protocols, and related instruments irrespective of controversy. To this point, Pedro, a Peruvian research coordinator and previously a peer-recruiter, described:

Obviously when the researcher tells me that he wants to recruit MSM he means gays, *mosteceros*, *fletes*, bisexuals, and until recently also *travesti*. I recruit who I can and say I recruited MSM...what matters for the researcher is that they [MSM] attend the clinic [for enrollment in study procedures]. (Pedro, interviewed August, 2017)

Recruiting ‘MSM’, as illustrated by Pedro, is an active process that requires cultural reinterpretation to achieve the objective of creating a research population. While it is evident that people on the ground involved in the fieldwork recognize the heterogeneity within the category, this reality is erased as diverse social identities are melded into one homogenous study population. The disconnect between expert-level requirements and on-the-ground realities illustrates the awkwardness that ensues when, despite distinct cultural contexts, the Peruvian research infrastructure is forced to adopt imported scientific population categories.

Due to the growth of Peruvian-led research and advances in in-country technology, NAMRID turned testing operations over to the Peruvian state in the early 1990s, ostensibly relinquishing its role as a central site of power. Yet, its legacy continued. NAMRID’s US-based understandings of risk infused the fabric of Peruvian scientific practice and knowledge, and continued to define baseline understandings of at-risk populations (e.g., MSM) and, post-20010, understandings of *most* at-risk populations, which includes transgender women as separate from MSM. Additionally, NAMRID established a precedent for US involvement in Peruvian research through formalized training pathways. Indeed, promising young Peruvian investigators, through initial contact with NAMRID, received opportunities to obtain master’s degrees in the US. These researchers included Jorge Sánchez, Carlos Cáceres, and others. As Dr. Alvarez, a senior Peruvian researcher, who participated in this training pathway explained, “We all knew that if you were able to go the US for a master’s, you could get a job doing research. Otherwise, you are

only a doctor” (Dr. Alvarez, interviewed July 2018). Dr. Benavides, another Peruvian biomedical researcher described, “I knew that if I wanted to continue to do research in Peru I needed to go to the US [for my master’s]. That is where I learned how to play this game... I am trying but the competition here [in Peru] is tough and you are always second to a US investigator” (Dr. Benavides, interviewed January 2018). Across interviews, it became clear that US training held symbolic capital and was used to differentiate and rank Peruvian researchers.

US training not only worked to elevate Peruvian physicians to physicians-researchers, but also developed into a sub-enterprise that allowed more senior actors to become gatekeepers to US education. Many young physicians recount that they were expected to “pay their dues” (e.g., work for limited money, ghostwrite papers, etc.) for the promise of a master’s. Notably, in such cases the senior Peruvian scholar financed neither the graduate degree nor living costs; rather, the US training programs covered all expenses. But it was the senior Peruvian scholar’s recommendation that functioned as a gateway, facilitating connections to US networks and enabling access to training pathways.

Beginning in 2002, this system shifted. Rather than sending Peruvians north via personalized recommendations, research centers established more formal training partnerships. The first large US-funded training grant was the International Clinical, Operational, and Health Services Research Training Award for AIDS and Tuberculosis (ICOHRTA) (National Institutes of Health (NIH), Research portfolio online reporting tools, n.d.), housed at the Universidad Peruana Cayetano Heredia (UPCH). ICOHRTA founded the Fogarty International Center (FIC) in Peru, aimed at training medical doctors in clinical, health services, and operational research. The original partner institutions were the University of Washington (UW) in Seattle and the University of Alabama (UA) at Birmingham. Notably, this wave of FIC training money to Peru

matched the Global Fund and NIH's initial economic investments to other institutions to build research infrastructure. Jointly, US-based initiatives infused Peru with vast amounts of HIV and AIDS-related funding that not only structured how research would be done and among whom, but elevated Peru into a central position to conduct offshore research due to this existing infrastructure.

According to Dr. Smith, a US expert with close to twenty years of experience working in Peru, it was these training grants that “put Peru on the HIV research map” (Dr. Smith, interviewed March 2017). Through these training partnerships, Peru became known not only as a site in which capable researchers could carry out HIV science in conversation with US practices, but also in which research policies were amicable to external funding and protocols—a result of the US's instrumental involvement in structuring the initial HIV research field, and continued maintenance work done by Peruvian expert scientists who benefited from US alliances. When discussing why they choose to work in Peru, US researchers frequently referenced Brazil as a counterexample, a country that restricted and placed barriers on US-lead research. With constant pressure to secure independent funding from the NIH, US researchers further identified the benefit of collaborating with US-trained Peruvian investigators who know how to *do* NIH grants.

As revealed throughout the course of my ethnographic fieldwork, the processes of doing this research is complex, requires performance, and intensive labor. Indeed, there are abundant indications of actively developing and employing a US model to structure the Peruvian field of HIV science. The Program for Advanced Research Capacities for AIDS (PARACAS; implemented in 2014), for example, melded aspects of two previous grants yet changed its focus from training early-career public health investigators to more explicitly fortifying existing pathways that allowed established Peruvian researchers to continue their work in a US-funded

research system. Specifically, it aimed to train mid-career HIV researchers to “reach scientific autonomy... [by] fostering the ‘thinking ahead model’... These strategies should serve to nurture new incoming generations of physician scientists whose contributions should continue to notoriously improve the lives of PLWHA [people living with HIV and AIDS]” (National Institutes of Health (NIH), Research portfolio online reporting tools, n.d.). In other words, PARACAS sought the autonomy to provide trainees with the necessary skills to develop careers as independent investigators following a US research model. A core component of this training grant was to teach Peruvian researchers how to successfully compete for research funding in US-based systems, using grants to conduct research without the financial support of their host academic institutions and thus maintaining the ability to abide by US research guidelines.

These South to North training pathways generally occur as a Peruvian researcher travels to the US (for a one-year master’s or residency program, or, on rare occasions, a PhD) and then returns back to Peru to conduct research in collaboration with US scientists (often the lead scientists on a given project). However, it is significant to point out that many US scientists have enhanced their own careers by being “trained” in Peru. Notably, this pathway is rarely recognized as training, but rather referred to as “fieldwork” or “part of my international portfolio.” For example, Ken, a US Fogarty scholar, recounted:

As a third-year medical student I took an international research year aiming to not only learn about global health but strengthen my residency applications. I have always been passionate about learning how to better serve vulnerable populations and my year in Lima taught me important lessons that I am able to translate to the US. (Ken, interviewed August 2017)

When speaking to Peruvian researchers about their professional relationships with US investigators, many scoff and refer to international health researchers’ imbalance of power. Importantly, this imbalance is not overt, but rather systemic. As highlighted by Dr. Castellano, a

Peruvian research assistant, “We get paid to get the work done but we are never in charge. They [Americans] come as students to learn and then become the PIs [principle investigators]” (Dr. Castellano, interviewed January 2018). That is not to suggest that there are no exceptions, and indeed there are several notable examples of American researchers who have moved to Lima to live and work according to the local context. But these *are* exceptions, not the norm.

Not all Peruvian research scientists perceive or voice this imbalance. In fact, several expressed gratitude for the training opportunity and note the transformative power Fogarty has had on Peruvian health politics. This perspective is best summarized by Dr. Patricia Garcia, professor and former dean of the School of Public Health at the Universidad Peruana Cayetano Heredia (UPCH) and the 2016-2017 Peruvian Minister of Health in her March 2018 interview with Fogarty International newsletter, *Global Health Matters*. In her words, “As an AITRP trainee (Fogarty AIDS International Training and Research Program), I learned what makes an enabling environment for research, and when I returned to Peru, I was able to create one at Cayetano Heredia's School of Public Health” (Fogarty International Center, n.d., p. 5). In response to the question “How did UCPH become a research powerhouse?”, she continues:

Fogarty gave many Peruvians the opportunity to train in the U.S. Second, we've been able to access numerous grants through Fogarty, including early career support that allows trainees to come back to Peru, and training grants that have allowed us to devise and implement our own programs...Fogarty has also taught us to network more effectively by giving us the opportunity to interact with U.S. researchers. (p.5)

Opinions on Fogarty and other global North training ‘alliances’ in Peru vary widely. Yet, perspectives commonly implicated NIH or Fogarty directly in the creation of the contemporary Peruvian research infrastructure and key actors within it. Particularly within the context of HIV treatment and prevention research. Garcia describes that training support is only one piece, and that the adoption of this training in the Peruvian context is what has been critical in the Peruvian

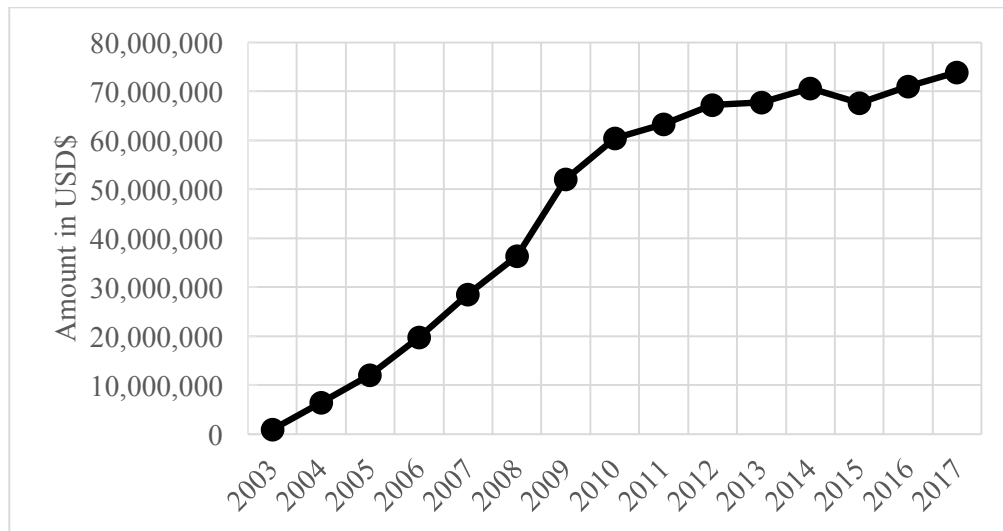
research success story. The creation of research infrastructure that converses with US systems has allowed for the continued flows of NIH funding. Furthermore, the ability to claim expertise in doing global health is linked to the ability to secure US grants, not only in the US context but in Peru as well. As one of Fogarty's most important alumna, Dr. Garcia, is a key example of what I term the *vision gringa*— the deep entanglement between the US and Peru responsible for structuring and maintaining how power has operated within this research arena. As she states, “I believe that every single step you take in life shapes who you are, and the steps I've walked with the help of Fogarty were instrumental in helping me to achieve a great deal, including being appointed health minister” (Fogarty International Center, n.d., p. 5)

Funding

Training pathways, like PARACAS, gained further prominence as they intersected with larger HIV politics and associated funding streams. Indeed, the rise in HIV science funding is critical to understanding why Peru has become a prime site for biomedical HIV prevention research focused on people of diverse genders and sexualities. From 2000 onward, growing North-South networks established through training pathways collided with new funding opportunities to conduct HIV research and programmatic work. Simultaneously, a global surge of funds emerged to fight HIV, referred to as HIV “scale-up” (Kenworthy & Parker, 2014). With a recognized ability to work within an established global North system, Peru received a disproportionate amount of funding compared to other countries in the region. Notably, these funds were predominately earmarked for gay community education and advocacy efforts. For example, between 2003 and 2017, Peru HIV and AIDS programs received slightly less than \$74 million (USD) from the Global Fund, making it the largest recipient in South America and

second largest in all of Latin America (The Global Fund, n.d.). For a visual of the steady investment made to Peru, see Figure 1.

Figure 1: Global Fund HIV/AIDS funding for Peru 2003-2017



In addition to community-based efforts funded by the Global Fund, the years since 2000 have shown a notable funding increase for public health research (namely from NIH) to investigate the concentrated burden of HIV among MSM in Peru. See Figure 2 in Chapter 3 for visual of NIH funding to Peru. This upsurge served as the primary motivator for Peruvian and global North researchers to unite and implement precedent-setting biomedical research among people categorized as MSM and, since 2005, transgender women. Funding from NIH takes various forms, including investigator-initiated grants (frequently referred to in interviews as the R-prefix series, e.g., R21, R34, and R01). All of these grants awarded from their inception until today illustrate Peruvian-US scientific entanglements at the expert-level; however, the US investigator is typically identified as the primary scientist (i.e., contact PI). This is an important distinction to note, as these partnerships are not equal and serve to disproportionately benefit

scientists from the global North though the work is managed by and conducted in Peru.

To further disentangle notions of imbalance, as described by Dr. Castellanos in the previous section, between US and Peruvian research alliances it is important to describe how funding is distributed and operates. As described to me by Dr. Greene (interviewed February 2017), an NIH program officer who actively manages grants led by US and Peruvian principal investigators, NIH funding awards include direct costs (expenditures budgeted for scientific research and listed in the public domain) and indirect costs (defined as expenditures related to facilities and administration). NIH does not determine indirect costs; rather each US academic institution establishes their own fee.

However, NIH does limit the number of indirect fees that a foreign institution can charge to 8%. For example, a typical R01 award is approximately \$2.5 million (USD)—\$500,000 annually for 5 years. In 2018, within the Harvard Medical System (including Harvard School of Public Health and Boston Children's Hospital), a recipient must account for 77% of their indirect costs. This compares to 51% at the University of California, Los Angeles and 62% at Columbia University. Notably, indirect costs are not money taken from the grant itself, but additional funds that NIH provides specifically for administrative purposes. In the case of a hypothetical R01 awarded to a Harvard-based investigator and Peruvian principal investigator at Universidad Peruana Cayetano Heredia (UPCH), about \$1.9 million (USD) would be allotted to Harvard, compared to \$200,000 (USD) to UPCH for grant administration costs (i.e., indirect costs).

This simplified example illustrates two key points. The first is the systemic imbalance between US-based and foreign sites with respect to funding allocation. While this relates to indirect—not direct—costs, it is important to note that, at least in the case of Peruvian HIV studies, all of the work takes place in the foreign site. The second point is that NIH funding has

created a context in which scientific research is an enterprise, not only for researchers but also for academic institutions. Starting in 1999 when the first NIH grant was awarded to study the Peruvian HIV epidemic among MSM, NIH funding entrenched and further structured HIV research within an already established *vision gringa* in Peru. NIH funding capitalized and further developed the existing infrastructure of US-Peruvian partnerships and a tradition of US-trained Peruvian researchers as a model of how to conduct global scientific research. Dr. Jones, a prominent US physician researcher, explained why NIH funding in Peru grew so quickly post-2000: “NIH grant growth in Peru was seamless... there were three essential components that facilitated this: investigator capacity, concentrated epidemic among MSM, and political will” (Dr. Jones, interviewed March 2018).

What Dr. Jones is referring to as a “concentrated epidemic among MSM”, isn’t as seamless as he describes. Especially, around 1999, when the initial NIH grants were given, there was still confusion and rejection of the term MSM and community-based suspicion of understandings of risk concentration. Paco, a gay-activist and involved in early NAMRU and UPCH research efforts to test gay men for HIV, described, “I remember those early years. Not only were we scared, but there seemed to be more confusion about who was at-risk... am I MSM? No, I am gay, but apparently not in research, in research I was an MSM” (Paco, interviewed August 2017). Later in our conversation, Paco further detailed the interest in research targeting gay men. In his words:

Since we first learned about HIV, people were interested in gay men, I mean [chuckling] MSM... My first job as a recruiter was around 2000, maybe 2001. By then there was an explosion of research on MSM. There was still confusion with who were and who weren’t MSM, but now there was money. So as a recruiter if the *gringos* told me they wanted MSM in their research and they paid me, I brought them MSM. (Paco, interviewed August 2017)

Gringo-lead research, as described by Paco, can occur in multiple ways, and investigator

initiated grants are only one aspect of how NIH money can fund HIV research. Large-scale networks, such as AIDS Clinical Trial Group (ACTG), HIV Prevention Trials (HPTN), and HIV Vaccine Trials (HVTN), are also funded by NIH but frequently include pharmaceutical industry support. Network grants are much more lucrative and awards are given to a consortium of institutions, rather than individual investigators. For example, HVTN “is the world’s largest publicly-funded international collaboration focused on the development of vaccines to prevent HIV/AIDS,” and Peru is one of only two sites in Latin America (HIV Vaccine Trials Network, n.d.). Notably, HVTN funding also predominately focused explicitly on MSM and funded the creation of Impacta, a research organization in Lima lead by Jorge Sánchez focused on HIV treatment and prevention for MSM. Today, Impacta has received “over \$43 million of NIH investment to establish comprehensive clinical and laboratorial infrastructure for designing and implementing DAIDS [Division of AIDS] scientific research studies, including those from the HVTN, HPTN, ACTG, MTN [Microbicides Trial Network] and INSIGHT [International Network for Strategic Initiatives in Global HIV Trials], as well as non-network clinical trials” (HIV Vaccine Trials Network, n.d.).

While NIH reports total funding, as that money is public and derived from tax-payer dollars, sub-awards—the amount of money given to the foreign institution to carry out the research—are not reported. Tracking the funds awarded to networks and partnering foreign sites is even more challenging; without public reporting of subcontracts (and network sub-awards), the money given to foreign sites remains hidden. As one global North researcher, Dr. Nelson, with previous R01 funding in Peru stated, disclosing sub-awards amounts is “at the discretion of each individual grants leadership team whether and how to disclose” and “good luck asking contact PI (principle investigator leading the study) to disclose... you might have more luck

asking the Peruvian sites if they track it” (Dr. Nelson, interviewed April 2017). Other interviews with global North experts described Peru as having received “enormous funds from the HVTN and HPTN” because “people look to do biomedical research in Peru due to existing infrastructure,” (Dr. Paulson, interviewed May 2017) but none could provide evidence of how much US NIH funding has gone to Peru, nor could they locate the resources to find these answers. See Appendix E for a list of NIH reported data on Peruvian scientist lead grant awards.

From 2003 through 2017, the Global Fund reported contributions of slightly less than \$74 million (USD). As a comparison, Impacta alone received more than \$43 million (USD) from HVTN/HPTN to set up clinical and laboratorial infrastructure (which does not include funds to conduct clinical trials), and while it is the most established site, it is one of only three sites active across these clinical trial networks. However, these reported funds are, at best, a gross underrepresentation due to the challenges in accessing information about funding awards. For example, between 1999 and 2006, a little over \$11 million (USD) was awarded for a study titled “NIMH Collaborative HIV/STD Prevention Trial” (U10MH061536) (Caballero et al., 2011). While this study originated as a collaboration between US and Peruvian scientists, in 2004 it grew to encompass five countries. Because of its ambiguous title and American lead investigator, the study was not listed as a Peru-based grant, even though five years of research were conducted exclusively in Peru. Instead, it is necessary to have prior knowledge of the study to make this link, and remains unknown how much of the \$11 million (USD) went directly to Peru.

These documented increases in global North funding demonstrate the expansion of scientific knowledge about HIV/AIDS, and scientific knowledge specifically about those most-at-risk—namely, MSM— as does the growth of publications. Between 1985 and 2010, approximately 257 articles related to HIV/AIDS epidemiology were published in Peru (Caballero et al., 2011).

Notably, these were mainly published in the past decade (close to 70% since 2003), are disproportionately printed in English, and focus on chronicling the risk profiles of MSM and other noted vulnerable communities (Caballero et al., 2011).

Importantly, during this post-2000 period, while Peru received an unprecedented influx of global science aid (i.e., US National Institutes of Health) and health aid funding (i.e., the Global Fund), especially compared to other countries in South America, it paralleled a global phenomenon of HIV scale-up. The excitement and resulting moves to match financial support to combat AIDS was exogenous to the Peruvian arena, and due to both global activist pressure and scientific advancements that fueled hope about treating the disease. The advent of combination drugs to suppress HIV viral loads were shown to ameliorate the burden of HIV on people's lives, with respect to both treatment and prevention. Consequently, the use of ARTs as a biomedical approach became a key strategy to treat not only those living with HIV, but also "at-risk" populations, ushering in a new paradigm of "treating-to-prevent" (Nguyen, 2010; Nguyen, Bajos, Dubois-Arber, O'Malley, & Pirkle, 2011b). The multiple uses of ARTs yielded a global optimism which transformed the emergent biomedical technology into a silver bullet, as reflected in the 2006 and 2008 international AIDS conference themes, "Time to Deliver" and "Universal Action Now."

In response to this optimism, available funding increased on a global scale; since 2000, bilateral and multilateral organizations have provided \$109.8 billion (USD) to fight HIV and AIDS (Schneider et al., 2016). This unprecedented financial backing for a singular health outcome underscores the collective political will and important actors/institutions committed to fighting HIV and AIDS. Yet what makes Peru unique in the Latin American region is that its status as a prime recipient of these funds is due to a research infrastructure created by the US—a

circumstance that facilitated a track record of successfully administering global funds and implementing research projects. Moreover, it was within this treating-to-prevent paradigm that Peru emerged as a lead site for global biomedical research among people of diverse sexualities and genders. As summarized by Tim Frasca, “In Peru, research historically was not utilized to further prevention; rather, the entire prevention apparatus existed to further research” (Frasca, 2005, p. 21).

After the global economic crisis of 2008, international aid for HIV and AIDS services in Peru diminished, leaving the state to provide treatment, educational campaigns, and the like (financed primarily by the Global Fund). But notably, international aid continued for research within the HIV prevention paradigm. During this time, Peru’s weakened scientific oversight and administrative requirements (as compared to neighboring countries, such as Brazil) began to incentivize a research climate conducive to HIV trials. Unsurprisingly, this resulted in an increase in US-funded biomedical research after 2010. This combination of factors has created numerous institutions that are able to understand and act in accordance with US biomedical research mandates, complete with Peruvian investigators leading research aligned with US priorities and state actors willing to implement bioethical standards that promote biomedical research. For example, after 2007, a clinical trial’s sponsor (e.g., NIH, HPTN) was no longer obligated to purchase insurance that covered research subjects from adverse effects (Quispe et al., 2012). The rationale was that the sponsor country (i.e., the foreign nation funding the research) would assume responsibility for monitoring and audits. However, in 2008, though 0.4 percent of Peruvians participated in US-sponsored clinical trials, the US Federal Food and Drug Administration (FDA) did not send a single inspector to Peru (Quispe et al., 2012) (Quispe et al., 2012).

In addition, while the research is conducted in Peru, the production and use of knowledge related to HIV science continues to be regulated and commercialized by the global North—an arrangement that several scholars have labeled “offshore” research (MacQueen, 2011; Petryna, 2007). The term refers to the phenomenon of situating research in sites that are removed from the sponsor’s country or region of origin. Notably, these offshore locations are often in the developing world, where research requirements are more relaxed and existing state-sponsored health services are weaker, and thus particularly work to benefit the research sponsor. Furthermore, research is often cheaper and easier to do, compared to countries in the global North, based on the availability of human capital and willing research subjects. Increasing flows of international funding for offshore research was part of the HIV “scale-up/scale-down” story in Peru, and as a result, the value of conducting research among MSM increased while global funding for HIV services declined.

One global North NIH-funded principal investigator with a decade of experience working in Peru, Dr. Erikson, described the specific economic value placed on HIV research focused on MSM and transgender women, stating, “We are all mercenaries” (Dr. Erikson, interviewed May 2018). Her word choice indicates the tension between the economic gains of HIV research and the ethical challenges arising from such heightened focus, when improvements to the burden of HIV among MSM and transgender women remain limited. Another Peruvian physician researcher, Dr. Galvez, used the phrase “for money the monkey will dance” (*por la plata baila el mono*) (Dr. Galvez, July 2017) to explain that financial incentives have been a key force driving HIV science for in-country researchers. However, there is more at stake. While money is a fundamental factor, prestige and ego must also be factored into the social capital attained by not only participating in this field, but also being internationally recognized as a leader.

While such leaders acknowledge the sustained US presence in Peru, opinions differ regarding how influential the US has been. As one prominent Peruvian biomedical researcher, Dr. Delmonte, described,

I wouldn't say that US and Peruvian interests conflict. It is US priorities, mainly in funding, that provide direction for the work we do in Peru... MSM are at-risk globally for HIV and the research in Peru helps us better understand which strategies work to stop HIV. (Dr. Delmonte, July 2017)

Several actively engaged biomedical researchers, both Peruvian and American, echoed this point that overlapping research priorities guide in-country efforts. And although some researchers voiced frustration about external forces governing their funding, many generally understood it as the reality of the situation.

Yet there are others who more forcefully critique the Peruvian-US relationship. “It is the *visión gringa* that created the Peruvian scientific agenda,” Juan Pablo, a HIV treatment activist, explained to me (Juan Pablo, interviewed August 2017). Dr. Funegra, a Peruvian physician-researcher, argued that “the northern agenda” dictates Peruvian research practices (Dr. Funegra, interviewed August 2017). These opinions are just two of many that cite an on-going power imbalance that favors the North at the expense of the South. *Visión gringa* captures the sentiment of deep entanglement between the US and Peru – one responsible for structuring and maintaining how power has operated within this research arena. It has facilitated Peru’s emergence as a hotbed of HIV science, actively creating the perfect conditions to conduct biomedical research: namely, US-trained Peruvian experts, supporting institutions, willing governments, and economic incentives fueling a marketplace controlled by and benefitting the North (e.g., funding and accolades).

As the US’s multipronged presence within the Peruvian field demonstrates, Northern institutions and scientists substantially influence the construction of scientific knowledge, both in

terms of what gets enough funding to be studied (i.e., MSM) and how the scientific knowledge produced therein is disseminated to a global audience. However, it would be a mistake to assume that Peruvians are subservient within this relationship. In the following section, I use intertwined stories of experts as an entry point to understanding the behind-the-scene struggles, existing hierarchies, motivations, and disruptions that drive the contemporary HIV field in Peru.

Peruvian Experts

In the same way that one cannot talk about the contemporary Peruvian HIV field without recognizing the early and continued presence of the US, one cannot understand the internal dynamics of the field without assessing its key actors – actors that have actually been empowered by US involvement. These actors’ stories uncover how US funding flows to Peru, how structures are maintained in the field, and how power has been consolidated among a few elite experts. This section asks: Who are the people that sustain this global hotbed of HIV research? And what are the mechanisms needed to maintain prominence within this field? I argue that power has been consolidated among those with the strongest ties to the US and, in turn, these few individuals have been able to secure continuous funding to “do” science in a way that is mutually beneficial for the US and Peru.

As highlighted by the 2006 *Science* article and corroborated in interviews, Jorge Sánchez and Carlos Cáceres are central to Peruvian HIV research. When asked about the major players, Dr. Delmonte, one key stakeholder added a third name, responding, “Well, obviously, the *niños genios de Cayetano* (the genius children of Cayetano).” Patricia Garcia joins Jorge Sánchez and Carlos Cáceres to form the trio recognized to dominate the field in Peru. Although they are brilliant researchers, the structure of the field – namely, US influence – has worked to empower

them in important ways, although each occupies a different position of power. Jorge Sánchez stands apart due to his involvement across private, academic, and public sectors, and especially among people of diverse genders and sexualities. As one of Sánchez' former colleague, Dr. Funegra, put it, “Whether you like him or hate him, one cannot deny that Jorge’s vision shaped and continues to dictate the Peruvian response to HIV” (Dr. Funegra, interviewed August 2017).

Having all been trained in medicine at the same private university, graduated within 5 years of each other, and at some point served as faculty at the top Peruvian private medical school (Universidad Peruana Cayetano Heredia [UPCH or Cayetano]), Sánchez, Cáceres, and Garcia share similar demographic characteristics reflecting the privilege and opportunities afforded too white, wealthy Peruvians. Additionally, they share another important qualification: US training. They did not arrive at this path by chance, but rather were guided by the same Peruvian mentor, Eduardo Gotuzzo, who served as a central interlocutor for the matriculation of students through existing global and Peruvian HIV research networks. In the words of a US-based researcher working in the HIV arena, Dr. Paulson, “I guess you could think of him as a ‘king-maker’ figure” (Dr. Paulson, Interviewed May 2017). Hugo, one of Gotuzzo’s former mentees who currently works as an HIV research coordinator, described him as a revered “old guard” who maintains relationships with all key players but rarely overtly engages in territorial politics (Hugo, interviewed July 2017).

This is not the case for the “*niños genios*.” The three actors have a volatile relationship—particularly Sánchez and Cáceres – that is central to the internationally circulating story told about the contemporary HIV arena in Peru. These tense relationships are common knowledge, and often flippantly referenced among other Peruvian researchers as well as those in the global North (J. Cohen, 2006). Yet, this fixation on Peruvian drama conceals a significant feature of the

larger global story: the power of US training and networks that facilitates sustained funding to a limited number of investigators.

Gotuzzo and Sánchez were among the first investigators to chronicle the initial 42 cases of AIDS in Peru between 1985 and 1988 (Cueto, 2001). Through his training at Cayetano and Gotuzzo's mentorship, Sánchez worked closely with NAMRID, and his connections there allowed him to travel to the 1991 International Pan-American Conference on AIDS held in the Dominican Republic. Sánchez was the first of many young promising Peruvian physicians to be trained in the US. As Sánchez recounted, his introduction to physician-researcher King Holmes (UW) facilitated a critical training opportunity that propelled his career. "I was the first in a lineage of over 70 Peruvians to receive funding to complete a Master in Public Health," he explained (Dr. Sánchez, interviewed August 2017). Sánchez's experience is emblematic of the pathway forged in the late 1990s to train Peruvians under a US model to enable the growth of "offshore" research compatible with US aims in the 2000s.

Following the completion of his master's degree, Sánchez continued to work for UW in Latin America. As he described in a personal interview:

They [UW] hired me to consult on their STI surveillance project throughout Central America, a program they had with USAID. This was between 1993 and 2000 more or less. In the beginning, I was traveling at least two weeks a month, to the Dominican Republic, Honduras, Nicaragua, and less so to Panama, El Salvador, Guatemala. I wrote the protocol for the sentinel surveillance for Central America and afterwards it was implemented. (Dr. Sánchez, interviewed August 2017)

This example demonstrates the breadth and reach of US influence, as Sánchez—trained in the US, funded by a US academic institution, and connected to global North flows of money—was able to implement US models for conducting public health science throughout Latin America. Importantly, UW's pilot program paralleled early efforts by NAMRID to emphasize the key role of STI surveillance among group populations deemed at-risk, namely MSM. In this way, major

US institutional power has helped to structure the framework for understanding disease surveillance not only in Peru, but also in the larger region. Moreover, that power and influence exported the category of MSM and cemented it within HIV science.

The early usage of MSM, on the one hand, allowed for the accumulation of descriptive epidemiological data to compare across Latin American as well as with trends in the US. On the other, it produced boundaries that limited sexual and gender fluidity, not only conflating behaviors (e.g., who has sex with whom) with biological factors (e.g., pathogens), but also flattening complex historical and sociopolitical dynamics associated with sexuality. As noted previously, this mode of scientific inquiry was already well established in Peru due to NAMRID and US-based investigators. Yet, Sánchez emerges as a prime example of a bridging mechanism to export this approach throughout Latin America, and actively maintain specific scientific processes (through study design, protocols, data, and dissemination) of HIV science.

In 1996, Sánchez became a central figure in the Peruvian government when he was named the director of the Special Program for the Control of AIDS (*Programa Especial de Control del Sida* [PECOS]). Under Alberto Fujimori's administration, Sánchez transformed PECOS from a special program to a national program: Program for the Control of Sexually Transmitted Diseases and AIDS (*Programa de Control de Enfermedades de Transmisión Sexual y Sida* [PROCETSS]). Yet, interestingly, Sánchez was not a Peruvian state employee, but rather continued to be paid by a US academic institution. He disclosed, "When I started working for the Ministry it was UW that paid me, not the Ministry. It wasn't until the last two years, maybe 1999 and 2000, that I was paid by the government" (Dr. Sánchez, interviewed August 2017).

However, it was not due to US influence that Sánchez became a political actor. His appointment resulted from Via Libre's pressure on the government to improve their response to

HIV/AIDS (Cueto, 2001). Notably, Sánchez was a founding member of Via Libre. Nonetheless, this is an example of the complicated connections between US and Peruvian interests and their resulting actions—it is almost impossible to disentangle where one begins and the other ends.

While in government, Sánchez championed HIV treatment and research. One of his key achievements was the allocation of state funds to his national program, PROCETSS, to establish a coordinated medical response to identify and treat HIV and STIs. Unsurprisingly, given Sánchez's training, understandings of at-risk populations and epidemiologically driven research characterized his achievements. For example, he created a network of specialized clinics by fortifying the existing PECOS clinics in Lima and establishing 33 new PROCETSS offices outside the city. In 1996, these PROCETSS clinics provided data for the first surveillance program and made HIV and AIDS case notification mandatory (Konda et al., 2007). While it was an understanding of MSM's vulnerability to HIV infection that drove Sánchez to emphasize the necessity of epidemiologic data proving the needs of specific communities, these efforts also had unintended consequences. Namely, increasing funding availability grew, so too did research focusing on Peruvian MSM. This circumstance increased competition among Peruvian scientists and further internally polarized research camps.

In the early 2000s, Sánchez left his position at the Ministry of Health to again focus on HIV research. Following his departure from government, Sánchez established a second NGO, *Asociación Civil Impacta Salud y Educación* (Impacta), in 2000. As he explained, "Impacta was created to do research. I was tired of politics and wanted to do the science that mattered" (Dr. Sánchez, interviewed August 2017). Impacta did this and more. Founding the NGO formalized Sánchez's status as an expert in HIV science and made Peru a key site within the large-scale global network of HIV clinical trials funded by the US NIH. "NIH demands so much

administrative work that it is almost impossible to do NIH research and anything else,” said Dr. Cruz a Peruvian physician-researcher who previously worked at Impacta (interviewed September 2017). With the increasing commercialization of clinical research and growing competition for research subjects, Impacta was the only NGO at the time structured to accommodate the research needs of multinational pharmaceutical corporations as well as privately sponsored clinical research.

Sánchez’s dominance in the Peruvian HIV landscape has even been described by US-collaborators as preternatural: “A longtime leader in Peru’s battle against AIDS, Sánchez’s superpower is research” (Engel, 2018). Even so, this does not diminish Cáceres and García’s presence and power in the field. These two actors further illustrate how only a few elite experts control this arena and how power is divided among them. Cáceres’s influence and rise to prominence also began at the start of the epidemic in Peru. In 1988, Carlos Cáceres made his mark on the production of HIV related scientific knowledge with the publication of his undergraduate thesis. His project, which was in collaboration with NAMRID, assessed HIV antibodies of asymptomatic gay men. Beyond furthering an epidemiological understanding of HIV, Cáceres was the first in Peru to overtly link homosexuality to HIV risks by introducing the concept of “risk factors” (Cueto, 2002). Though previous US-Peruvian research called attention to the concentration of syphilis, HIV, and other sexually transmitted infections among bisexual and homosexual men (Cueto, 2002), Cáceres’s use of the term “risk factor” solidified the association between risk and homosexuality and focused attention on MSM. Similarly, years later, multiple experts noted that it was, again, Cáceres who flagged the need to distinguish transgender women as a separate risk category from MSM.

While Cáceres’s path similarly started at UPCH under Gotuzzo’s mentorship and

progressed to training in the US, his interests focused on how the social and behavioral aspects of the HIV epidemic intertwined with the biological. For example, his 1996 doctoral dissertation from UC Berkeley School of Public Health created a taxonomy of different sexualities within the umbrella risk category MSM (Caceres, 1996). His interests in HIV's social context shaped the boundaries he drew to denote which aspects of the HIV landscape fell under his domain. Cáceres straddles both social science interests and biomedical pursuits. His scholarship critiquing international aid and the Peruvian state's response to the HIV epidemic, and his initial criticism of pre-exposure prophylaxis (PrEP) are among his notable contributions to understanding the development of HIV science in Peru (Amaya, Caceres, Spicer, & Balabanova, 2014; Caceres, Aggleton, & Galea, 2008; Caceres et al., 2009; Cáceres & Mendoza, 2009).

Cáceres has also been an active player in global North-funded biomedical research. For example, he was the in-country principal investigator for a large, five-country randomized trial that assessed the role of community-level popular opinion leaders (CPOL) in leading HIV preventive efforts (Caceres et al., 2007). CPOL¹² was the first large-scale randomized trial among MSM conducted in Peru and, notably, was funded by the US NIH. It also marks the first in a lineage of trials that Cáceres conducted in collaboration with US partners, namely, the University of California (Berkeley and Los Angeles).

Similarly, as the final key actor comprising the “*niños genios*” trio, Patricia Garcia's strategic social positioning further reveals the internal structure of Peruvian HIV research—specifically its internal divisions. Garcia's current standing as a leading expert in HIV science is evidenced by her training and alliances with US experts and impressive career milestones,

¹² This study was referenced earlier in the chapter under its official name, “NIMH Collaborative HIV/STD Prevention Trial” (U10MH061536), and by lead US investigator Thomas Coates, as it appears on official NIH reporting documents. Cáceres was the Peruvian principal investigator from 1999 and 2006; however, it is unknown how much of the more than \$11 million (USD) went directly to Peru.

including her appointment as Dean of UPCH's School of Public Health from 2011 to 2016 and, more recently, her position as Peruvian Minister of Health from July 2016 through September 2017. Garcia further illustrates the entwined relationship between social capital (US alliances), position (recognition as a key player in HIV science), and strategic actions (career paths) within this HIV research arena. After graduating from Cayetano in 1988, Garcia, mentored by Gotuzzo, completed her residency and proceeded to obtain a Master of Public Health (1998) at the University of Washington (UW). Through partnerships with UW researchers and again, King Holmes, Garcia returned to Peru to embark on HIV clinical trials. However, armed with her US master's degree and residency, she arrived with a clear idea of her research territory: women, including female sex workers and pregnant women.

The study that elevated Garcia to international prominence in HIV science was PREVEN, a large community-randomized clinical trial across 20 Peruvian cities that assessed the effects of numerous prevention modalities on various sexually transmitted infectious, including HIV (García et al., 2012). While Garcia had previously participated in research with Sánchez and Gotuzzo that targeted people categorized as MSM, PREVEN's focus was on women and heterosexual transmission. As described in interviews with numerous Peruvian and US physician-researchers, this choice of research population was strategic, emblematic of a territorial claim intended to separate Garcia from Sánchez and Cáceres. However, in the last 9 months of the study, PREVEN's focus population shifted to include MSM and male sex-workers (Donovan & Guy, 2012). While the main findings paper (published in the top medical journal, *The Lancet*) does not address the rationale for expanding the population, Franco, who worked as a peer recruiter on several HIV studies including PREVEN and CPOL, makes the case that the motivation was a surge in funding for studies related to MSM. In his words, "In PREVEN at the

end, at the very end, Patty moved to include some MSM in the study... there was money for MSM and Patty wanted a piece” (Franco, interviewed July 2017).

Amidst this landscape, the schisms that emerged between these powerful actors and the scientific populations claimed by each, showcase how international flows of money dictate strategic career choices. For example, Garcia and Cáceres’s strained relationship was a result of more than a mere overlap in research population; rather, it was a power struggle over positioning in the field due to increased funding for research focusing on MSM. As described by Dr. Benites, an HIV researcher working with Cáceres at the time, “Don’t forget about the clash between their team [Garcia’s] and the CPOL study, as they claim that Carlos’s team encroached on their turf in the areas north of Lima, and there was a big fight over territory” (Dr. Benites, interviewed May 2017).

While the early Garcia/Cáceres tension shows friction, it is the lasting Cáceres/Sánchez rivalry (described in the next section) that became known throughout the world and helped to popularize the Peruvian HIV research arena as a *telenovela* (J. Cohen, 2006). The key distinction between these two powerful actors and Garcia is that they were vying for ownership of HIV research among MSM, whereas Garcia began to differentiate herself as an expert on HIV among women. Dr. Arizmendi, a physician-epidemiologist who has worked with all three actors at different times in his career explained, “You should think of it [research focus] as they [the three key social actors] think of it, as their personal fiefdom. Individual interest and competing agendas are at the heart of what research gets done” (Dr. Arizmendi, interviewed December 2017). However, it is this story of drama and intrigue circulated in Peru and around the globe that strategically hides the underlying major player: the *visión gringa* itself. As history makes clear, these research territories reflect larger constraints within HIV science, namely, US involvement

and resources that dictate the type of research allowed to be conducted.

Golden Opportunity: iPrEx

The lesson to learn from these actors is that there are structural aspects within the Peruvian research arena that have created a pathway: medical expertise, US training, and international networks, which jointly foster an elite social and scientific position. This pathway extends beyond these actors, and as history illustrates, reflects a deep entanglement between the US and Peruvian that has profoundly shaped the Peruvian research arena. However, all actors do not benefit equally, rather, this structure can limit the actions and strategies of Peruvian experts, despite bringing them success. Said differently, their agency is bound by the greater rules of the game, forcing research to be conducted ways that align with US goals and, by extension, the goals of global HIV science. This symbiotic relationship is rewarded by funding and international recognition, but only when paralleling major trends in the broader HIV research domain (e.g., at-risk populations). Yet, this is not to say that the structure negates agency; rather, the field is dynamic and there are examples of golden opportunities that have changed how the Peruvian field is positioned in the global arena, as well as how strategic actors engage with each other.

The post-2000 landscape for global HIV funding was marked by unprecedented quantities of international money to conduct HIV science. These funds were not administered equally across global regions, but rather strategically. At this time, Peru, while known in the global HIV research arena for training grants and the subsequent availability of highly skilled physician-researchers, only had a few small- to mid-scale global North funded HIV science grants. However, the advent of the *Iniciativa Profilaxis Pre-Exposición* (iPrEX) study shifted the

scope of possibility for Peru and propelled the field to another level: an ideal marketplace for HIV biomedical prevention research among most-at risk populations.

iPrEX was conducted globally between 2007 and 2011 at a cost of more than \$43 million (J. Cohen, 2010). It became the first multinational human study of an HIV prevention strategy known as pre-exposure prophylaxis (PrEP) conducted among MSM and transgender women (Grant et al. 2010). PrEP, also referred to by its commercial name, Truvada, is a combination of two HIV medicines (tenofovir and emtricitabine), intended for daily use as an intervention to prevent people from acquiring HIV. Said differently, PrEP is a combination of ARTs (the same drugs prescribed to people living with HIV) for people who are HIV-negative, intended to keep them negative. Importantly, iPrEX started as grant exclusively for Peruvian research and grew in size and scope to seven additional sites.

What is notable about iPrEX is that it was instituted following a number of failed PrEP trials conducted among women and commercial sex workers in Nigeria, Cambodia, and Cameroon (J. Cohen, 2004; M. S. Cohen, Muessig, Smith, Powers, & Kashuba, 2012).¹³ As described by both global North and Peruvian experts, Peru emerged as prime site to “try again,” but this time among MSM and TW. The rationale was two-fold. First, the epidemiologic profile of the Peruvian epidemic documented MSM as a population at heightened risk of HIV acquisition and transmission. Furthermore, widespread use of the category MSM cemented its legitimacy in biomedical research. Second, a strong research infrastructure that had already been tried and tested due to the historical legacy and prominence of HIV research focusing on MSM.

¹³ In 2004, the Cambodian prime minister quickly halted a trial of PrEP among Cambodian sex workers due to pressure from activists and NGOs (J. Cohen, 2004). This Cambodian-based protest migrated to the global sphere at the 24th International AIDS Conference in Thailand (Chase & Naik, 2004). About seven months later, in February 2005, the Ministry of Health stopped a similar trial in Cameroon due to activists’ concerns about safety and study procedures (Mills et al., 2005). In March 2005, the Nigerian arm of PrEP trials was discontinued prematurely due to failure to comply with safety and operational procedures (Singh & Mills, 2005).

Peru had the existing expertise of US-trained Peruvian physician-researchers, research institutes able to carry out complex protocols, experienced peer-recruiters, and an increasingly available study population of people classified as MSM. Notably, iPrEX started as a single country study, based in Peru, but grew in size and scope as the feasibility of conducting a more widespread study became clear.

Initial discussions between US and Peruvian investigators began in 2004 and by 2005, more formalized networks (as evidenced through a co-authored editorial promoting PrEP science; (Grant, 2005) were established to ramp up efforts to conduct PrEP clinical trial among MSM. iPrEX, though it was not the first clinical trial to assess PrEP (see PrEP Timeline Appendix D), proved to be a watershed moment, reinvigorating enthusiasm for PrEP after previous trials were marred in critique and failure. Given the positive results, efficacy, and acceptability of iPrEX, this study rolled over into an open-label extension: iPrEX OLE.¹⁴ Notably, across this global study, Peru came to represent more than half of the entire sample population. Patton and Kim highlight the significance of this demographic breakdown, stating, “In between the lines, but there for all to see, is the reality that the initial phase was an offshore trial in Peru” (Patton & Kim, 2012, p. 300). An increase in clinical research conducted in global South settings is not unique to iPrEX; however, iPrEX illustrates the ways in which the developing world is often treated as a living laboratory, justified by the need to test technological innovation to achieve social progress (Fejerskov, 2017).

Another significance of this demographic breakdown is that it evidences Peruvian

¹⁴ Between June 2011 and June 2012, the iPrEX OLE enrolled individuals who had participated in one of three previously completed PrEP clinical trials. Participants who enrolled in the OLE were offered “open label” PrEP (daily use of Truvada) free of charge, and were then followed for 72 weeks (Grant et al., 2014).

scientists' ability to "capture" populations of people categorized as MSM, which had previously been labeled as "hard-to-reach." This success facilitated a lucrative market around PrEP in Peru post-iPrEX, with the emergence of numerous additional biomedical studies among MSM and, later, transgender women. Thus, iPrEX became a strategic opportunity for both the Peruvian HIV research field and for actors within it, including Peruvian experts not involved in the original study.

However, two years prior to the start of iPrEX, in 2005, Cáceres emerged as a whistleblower during initial discussions about conducting an auxiliary study of PrEP in Peru (P. Goicochea, 2007). As one of the premiere HIV scientists in Peru, Cáceres's public stance against PrEP launched him into international circles, as he engaged in global discourse regarding the ethics of PrEP and scientists around the world sought his "buy in." According to Dr. Jones, a US investigator who worked in Peru before, during, and after iPrEX but was not directly involved in the study, "From what I could tell, being anti-PrEP made Carlos a player in a way he never was before" (Dr. Jones, interviewed March 2018).

Cáceres marked his anti-PrEP position in private emails to influential feminist and human rights activists, calling attention to critiques of PrEP that were circulating globally. However, he also laid bare his own politics and the existing competition:

Due to the existing doubts regarding this institution (I understand that some of you have already heard concerns about Impacta), and perhaps leaving aside an attitude of indifference trying not to monitor the work of this NGO (given that it could be interpreted as a conflict of interest due to competition), I feel it is important for me to voice my concerns.

His motivations were complicated, but his points were not unfounded. Cáceres was concerned about the incentive structure of the study, which some regarded as economically coercing participation, as well as the ethics of randomizing over 1,000 "high-risk" people categorized as

MSM and TW. Yet, several key informants felt that the reason Cáceres spearheaded efforts to stop iPrEX and emerged as the primary dissident voice was because he was not directly involved in what was projected to be (and in fact became) a landmark study. Rather, Jorge Sánchez along with his mentee, Javier Lama, and NGO, Impacta, were chosen to lead these efforts.

Significantly and in contrast to other PrEP controversies (e.g., Cameroon, Cambodia, Nigeria, etc.), which were led by activists (J. Cohen, 2004), the Peruvian case exemplifies a scientist-led critique. As an interesting aside, in personal conversations with Cáceres and Sánchez, both rejected being identified as activists. Rather, they voiced a preference for being labeled as scientists, researchers, and facilitators between HIV science and affected communities. While Peruvian iPrEX controversy was scientist-lead, it gained traction through building alliances with well-known and vocal activist organizations. Specifically, activist critics were concerned about the ethical implications of administering a medication (PrEP) that was not approved in-country and testing PrEP against standard of care¹⁵. Their reproach grew so loud that it ultimately forced government officials and agencies to take a stand and develop policies regulating medical experimentation on vulnerable populations. Moreover, as a result, the Peruvian Ministry of Health, numerous ethics committees (including ones at UPCH and UCSF), and activist organizations like Promsex and MHOL were included in discussions related to the

¹⁵ This argument links to historical antecedents that are worth mentioning. A major controversy was sparked by the 1994 trial testing drug regimens of short-course AZT among pregnant women in Africa, referenced as ACTG 076. ACTG 076 is an illustrative example of the underlining inequalities shaping the ethics of HIV science. By unmasking the unethical practices embedded within research design, the tragedy of a “world economic order that makes effective prophylaxis... available but unaffordable for many” was laid bare (Bayer, 1998, p. 570). Social scientist Adriana Petryna has further argued that the quest for the best science (i.e., placebo-control studies) introduces ethical variability regarding what types of people and contexts can be ethically exposed to placebos (Petryna, 2005). Social scientists have argued that the lack of ethical standards for the ways in which drugs are tested globally showcase the embedded inequality and legitimization of an ethical double standard in which some human lives are valued above others (Abadie, 2010; Fujimura & Chou, 1994; Hawkins & Emanuel, 2008; Petryna, 2007; 2009).

rise of biomedical interventions among communities categorized as MSM and transgender women. While the critiques of other failed PrEP studies centered on the trials' impact on the lives of the people enrolled as study populations—namely, economic coercion and the ethics of randomization, as one group received PrEP and the other a placebo—these issues remained unchanged in the final iPrEX protocol and the study's implementation in Peru.

Alerted about Cáceres's efforts to undermine Impacta and raise doubts about iPrEX, Sánchez sought to minimize the emerging critique by tapping into his domestic and international network of experts. This included numerous in-country visits from global North experts and presentations (to both community activists and government stakeholders) highlighting the novelty of the proposed intervention as well as documented “successes” in other PrEP trial sites. iPrEX did go on as planned, but not until April 2008, due to these controversies.

In 2010, the global iPrEX study showed that PrEP reduced the rate of new infections by 42% (Grant et al., 2010). However, after study end, Sánchez changed his position. No longer advocating for PrEP, he began questioning studies' ethics, and finally called for more research to assess feasibility—a stance that paved the way for Sánchez and his research organization to lead efforts into testing PrEP in 'real-life' context. Cáceres, interestingly, was by this time no longer opposed to PrEP, but rather, like Sánchez, advocated for more research, now positioning himself as a social epidemiologist in opposition to Sánchez's established biomedical expertise.

Post-iPrEX, Sánchez and Cáceres were not overtly on opposite sides of the PrEP argument, as was the case before iPrEX. However, they also did not unite to achieve common goals. Instead, they leveraged iPrEX as an opportunity to garner further funding and continue to develop the existing research apparatus. In this context, they manipulated their critiques into an opportunity to conduct more research. Furthermore, iPrEX was unique in that it garnered support

from Gilead, the pharmaceutical company that makes Truvada. Gilead not only donated the medication for iPrEX but also the subsequent open-label extension and, as of 2014, begun to facilitate privately funded drug testing in Peru. As a result, iPrEX served as a strategic opportunity to position Peru as a leading offshore HIV biomedical prevention research arena and a site amenable to collaborative ventures with Big Pharma.

Said differently, iPrEX serves to illustrate the confluence of factors that have jointly molded Peru into the perfect field in which to conduct biomedical research. In addition, the study's influence has worked to maintain funding to Peru despite the 2008 global economic downturn and subsequent HIV scale-down, and was the first in a series of clinical trials focused on MSM and transgender women that for which Peru has become known for in the contemporary research landscape. Indeed, iPrEX emerges as a pivotal moment wherein Peru became an international site for offshore HIV science research among MSM and, through iPrEX, transgender women. Notably, transgender women were recruited at MSM for iPrEX and, years later, re-analyzed as a separate scientific population (Deutsch et al., 2015).

Peruvians represented over half of the global sample for the watershed iPrEX trial demonstrating the efficacy of PrEP for HIV prevention (Grant et al., 2010). By 2012, the World Health Organization named PrEP as the only endorsed antiretroviral medication to prevent HIV among populations most at-risk as a guideline, and by 2014 as an official recommendation (World Health Organization (WHO), 2015). Yet, PrEP was not approved in Peru until 2016, eight years after PrEP was shown to be an effective for preventing HIV. Today, only name brand PrEP (Truvada, manufactured by Gilead Sciences) is approved for use but it has not been incorporated into the Peruvian public system. Importantly, unlike the scientist-lead push to involve various government ministries and activist organizations to understand the potential

utility of PrEP pre-iPrEX, similar efforts to translate science into public policy and promote access to PrEP post-iPrEX can be said to have lagged, at best.

Nonetheless while access to PrEP in Peru is restricted by cost and limited availability, PrEP-related research has flourished. Starting in 2017, Cáceres became the lead researcher for a multi-country PrEP demonstration study. Ironically, gay activists' and physician-researchers' critiques of the study parallel some of the initial issues highlighted by Cáceres himself at the beginning of iPrEX; for example, economic coercion due to incentives and sustainability outside of a study setting. And in 2018, ten years after the start of iPrEX, demonstration and feasibility studies lead by Cáceres, Sánchez, and others continue. The Peruvian research climate has further facilitated the use of branded drugs (versus generic versions of PrEP), thus empowering Big Pharma alongside NIH to continue this research among people categorized as MSM and transgender women. Importantly, these key investigators and their research hubs remain at the center of these projects.

An ideal biomedical research site

History is critical to understanding why Peru has become a prime site for biomedical research among people of diverse genders and sexualities. While the 2006 *Science* article points to interpersonal dramas that have captured international attention and created a snapshot of the research arena, it overlooked the existing rules and structured pathways, reinforced through funding opportunities and other US involvement, that have enabled Peru to achieve this status in the first place. Indeed, emphasis on the Peruvian *telenovela* diverts attention from the complex practices of doing global health research that introduce new and reinforcing pre-existing inequalities in the global South.

I have shown that when HIV appeared onto the Peruvian scene, the US naval base and associate US scientists made key decisions that structured the course of how the Peruvian epidemic was understood and the corresponding response. The financial and social investments from the global North in Peru created Peruvian HIV science as a system linked to transnational agencies and private partners' support. In broad strokes, these structural pillars included formalized pathways which trained promising young Peruvian physicians to become physician-researchers within a US model and incentivized continual connections with the global North. This structure has worked to shape key scientific actors as well as the larger field of HIV science in ways that align with US priorities (i.e., classifications of people at-risk for HIV), both in Peru and around the globe.

This chapter argues that iPrEx emerges as a clear example demonstrating how global North flows of money paired with US-Peruvian partnerships have created an ideal biomedical research marketplace among people categorized as MSM and transgender women. Given the 'successes' of iPrEx, today, Peru has attained unique global standing as a magnet for HIV clinical and behavioral research trials among people of diverse genders and sexualities. However, it is a research marketplace, whereby research begets more research to produce scientific knowledge that models and is in line with US practices. In the following chapter, I examine the economic and social value of *doing* research with and on people categorized as MSM and transgender and what this research means from the perspective of people categorized as MSM and/or transgender.

Chapter 3

Commodified Identities

Dr. Myron Cohen, the co-Principal Investigator of the HIV Prevention Trial Network (HPTN) and associate vice chancellor for global health at the University of North Carolina at Chapel Hill, took the stage at the 2018 regional Latin American HPTN meeting in Lima, Peru. He announced, “South America is the lifeblood of the trials network”—a statement that garnered clear enthusiasm among meeting attendees, proud that their research was being recognized as central to the advancement of HIV prevention science.

Yet Dr. Cohen’s statement is quite striking, even surprising considering the global magnitude of the trials network and where most of the research is conducted. HPTN, often in collaboration with the HIV Vaccine Trials Network (HVTN), is the largest clinical trials network dedicated to the development of HIV prevention technologies in the world, and the majority of HPTN/HVTN research sites—and of most global HIV research funding to date—has been concentrated in Sub-Saharan Africa, not South America. So what makes the research conducted in South America valuable enough, in Dr. Cohen’s estimation, to sustain the network?

I asked other members of the HPTN/HVTN leadership group and experts in HIV biomedical prevention variations of this question to gain clarity as to what Dr. Cohen meant. They added an important caveat. Dr. Lock, a principle investigator for HPTN 083,¹⁶ explained, “South America, but really sites in Peru, have led the charge in HIV prevention research on

¹⁶ HPTN 083 refers to the HIV Prevention Trials Network active protocol number 083, conducted globally to assess the efficacy of the long-acting injectable cabotegravir for pre-exposure prophylaxis (PrEP). Notably, this study is being conducted among HIV-uninfected men and transgender women who have sex with men (MSM and TW). There are over 80 HPTN 083 study sites across 15 countries. More information is available on the HPTN 083 website: <https://www.hptn.org/research/studies/hptn083>.

MSM and transgender women for the network. Efforts focused on the general population tend to be concentrated in Africa” (Dr. Lock, interviewed May 2017). Other experts further detailed two factors that make Peru particularly valuable for the network today and, more importantly, for future studies. The first is the high prevalence of HIV among Peruvians classified as MSM (men who have sex with men) and transgender women, and the second is Peru’s existing research infrastructure.

In the words of Dr. Black, US physician and HPTN researcher, “MSM research is crucial to the next phase of prevention science, and South America is an opportune place to test prevention modalities, given the high prevalence of HIV” (Dr. Black, interviewed May 2017). Moreover, according to Dr. Pérez, Peruvian physician and HPTN site investigator, “Peru, unlike many other countries in Latin America, has the infrastructure to meet the demands of HPTN protocols” (Dr. Pérez, interviewed May 2017)¹⁷. These insights shed light on Peru’s utility for a certain kind of HIV prevention research, namely, that which engages MSM and transgender women as research subjects. Indeed, deeply entwined local and global research markets have emerged around these biomedical categories related to gender and sexuality. These markets, which include HPTN/HVTN as well as NIH-funded biomedical research, are intended to meet the broader demands of the global HIV prevention industry’s current focus on biomedical prevention strategies for “at-risk” populations.

The previous chapter described the historical and political factors that transformed Peru into a unique biomedical research site with an infrastructure to sustain the global HIV prevention

¹⁷ As noted in Chapter 2, legislative changes to the regulation of clinical trials enacted after 2007 weakened scientific oversight to incentivize global North-led drug trials (Quispe et al., 2012). With this change, a trial’s sponsor (e.g., NIH, HPTN) was no longer obligated to purchase insurance that covered research subjects from adverse effects (Quispe et al., 2012). The rationale was that the sponsor country (i.e., the foreign nation funding the research) would assume responsibility for monitoring and audits. However, in 2008, though 0.4 percent of Peruvians participated in US-sponsored clinical trials, the US Federal Food and Drug Administration (FDA) did not send a single inspector to Peru (Quispe et al., 2012).

industry's needs. In this case, US institutions (e.g., US Naval Research Outpost) and scientists' early involvement helped to structure the Peruvian research arena to be in line with global North demands. Moreover, in the larger context of increased HIV research focused on people categorized as MSM and transgender women, the US role in defining populations considered most-at risk for HIV created standardized terms and information about these population categories. This standardization was subsequently fortified through continued US-Peruvian partnerships that formalized training and funding pathways (i.e., NIH).

A number of prominent research scientists discussed the Peruvian success story in a 2018 article published in the premiere medical journal, *The Lancet*¹⁸:

What are the consequences of this marked increase in research in Peru? This group of scientists have [*sic*] been entrepreneurial, bringing major international funding to the local research enterprise, beyond that available from the government, which has seeded the creation of jobs and improved our understanding and treatment of health conditions that are prevalent in Peru but less common or more difficult to study in other settings. (Glass, García, Belter, Livinski, & Leon-Velarde, 2018 p.e728)

This explanation illustrates the transnational economy of clinical trials and the neoliberal orientation of global clinical research. The use of terms such as “research enterprise” and the description of scientists as “entrepreneurial” highlight the relationship between capitalism and biomedical research practices in Peru that reflects global trends. Indeed, the authors present this relationship as a benefit that helped Peru flourish as a research site in the global biomedical economy.

However, citing examples from other global contexts, social science scholars have argued that this articulation of capital and human subject experimentation takes advantage of

¹⁸ As an interesting aside, Dr. Roger Glass, the first author, is the Director of the Fogarty International Center and Associate Director for International Research since 2006 and has never having conducted research in Peru. Notably, Dr. Patricia Garcia is the second author. See Chapter 2 for Dr. Garcia's important role in the Peruvian biomedical industry.

geopolitical inequalities with regard to medical care, research regulation, and at times postcolonial power dynamics (Abadie, 2010; Cooper & Waldby, 2014; Crane, 2013; French & Miller, 2012; Nguyen, 2010; Petryna, 2009; Rajan, 2006; Yates-Doerr, 2017). This critical scholarship draws attention to the ways in which contemporary research practices seek out individuals who are predisposed to become experimental subjects, creating “a form of currency in a transactional research economy fueled by data” (Crane, 2013, p. 7). While this literature has analyzed the commodification of human bodies and biological materials (Cooper & Waldby, 2014; Novas, 2006; Petersen & Krisjansen, 2015), there has been less attention to how the identities associated with those bodies are linked to their value.

This chapter tackles the concept of value—economic, social, and cultural—embedded within HIV prevention trials focusing on people categorized as MSM and transgender, not only regarding expert researchers, but also staff and research participants. Since contemporary HIV politics emphasize prevention, there is a spotlight on the social life of at-risk data. I argue that value is derived in multiple ways within this context. Most visibly, value is attributed to the data itself—blood, hair samples, and other biological material from human subjects deemed most at-risk for HIV (i.e., risk data). Significantly, data on risk behaviors is also included in this category. Surveys, some of which take more than an hour to complete, capture intimate details about sexual desires and behaviors, such as positions, frequency, and condom use. In this way, the commodification of gender and sexually diverse identities operates as a mechanism to access specific kinds of bodies and associated risk data for the HIV marketplace. Moreover, I argue that the categories themselves also have value. By claiming membership within or expertise on MSM and transgender communities, entrepreneurial opportunities emerge for both scientists and the people who are classified in this way.

To make these arguments, I borrow from Arjun Appadurai's (1986) notion of a social life of things as a particularly useful analytic to explore how data specific to Peruvians of diverse genders and sexualities circulate through and become commodified within the complex processes of the global HIV industry. I also engage science studies scholarship that has analyzed the ways that racial differences have been constructed and leveraged in biomedicine and for scientific value (Bolnick et al., 2007; Epstein, 2008; Kahn, 2013; Nelson, 2016; Pollock, 2012; Roberts, 2011; Vasquez & García-Deister, 2019; Wailoo, Nelson, & Lee, 2012). I both lean on and deviate from this literature by focusing on the commodification of gender and sexual identity categories rather than racial and ethnic categories.

This chapter is divided into three sections. The first details researchers' considerable investment in collecting and trading information about people categorized as MSM and transgender women—those who are deemed most at-risk for contracting HIV. Scientists exchange this information as a currency that, through pathways such as funding and publication, buys expertise and prominence in both local and transnational markets. The second section draws attention to the social practices that structure the ways that scientists conduct HIV prevention research to show how the categories of MSM and transgender women are produced as both commodities and assets, which are then leveraged within the global HIV prevention research economy. Finally, the third section turns to the people associated with these biomedical categories, demonstrating the culturally and historically specific ways that Peruvian gender and sexually diverse communities extract value from these identities. Indeed, claiming “MSM” and/or “transgender woman” as an identity offers specific benefits to these marginalized communities, such as access to healthcare and economic remuneration via trial participation and employment and for the creation of, bounded, opportunities for community mobilization.

However, these advantages often pale in comparison to those that scientists, particularly those based in the global North, are able to obtain in this industry. In this way, this chapter argues that capitalist practices operate to commodify marginalized identities and transform HIV prevention research into an economic venture.

Data Arbitrage in Clinical Trials

In economics, arbitrage refers to the act of profiting from the purchase and sale of a commodity that is valued differently across markets. For example, if a hypothetical stock is valued at \$10 USD on the New York Stock Exchange (NYSE), but at \$10.10 USD on the London Stock Exchange (LSE), the act of buying the stock on the NYSE and then selling it on the LSE would exploit this difference in price and earn the arbitrageur an additional \$0.10 USD per share. The commodity in question, valued differently across markets, must be mobile to be traded and must travel in order to earn a profit.

Applied to the HIV industry, the value in arbitrage comes from the ability to collect data in one location—where it is cheaper and easier to do so based on the availability of human capital and willing research subjects—and move it to another market where it can be better leveraged. This concept is illustrated by a conversation I had with Dr. Dover, a US investigator with active research projects that simultaneously include sites in Peru and the US. He explained the benefits of doing clinical research in Peru:

Without a doubt, it is harder to get funds to do international HIV research in Peru versus, say, Sub-Saharan Africa. But there is a case to be made for Peru. Peru is a unique place to assess novel HIV prevention solutions among the most at-risk populations... The argument we always make in our NIH grant applications is that research in Peru is necessary to understand and better address the dynamics of a concentrated epidemic versus a generalized epidemic. Data from Peru is urgently needed to inform future studies and global prevention efforts to stop the spread of HIV. This research is not only important for understanding the Peruvian epidemic but also the epidemic in the US...

MSM and transgender women are also at heightened risk for HIV in the US, but not the magnitude we see in Lima. (Dr. Dover, interviewed January 2018)

As Dr. Dover's perspective illustrates, doing research on MSM and transgender women in Peru has value because of global North funding and associated prestige, but what is more important is the economic potential of future research. Said differently, while participants and researchers in Peru do receive economic remuneration, the real value in collecting data from these at-risk populations (risk data) is in its extraction from Peru and circulation in the global HIV prevention research marketplace. Ultimately, its potential value extends even further; if prevention research is transformed into prevention practice, Big Pharma can stand to earn a great deal if the pipeline is successful.

Dr. Dover's statement also points to the intertwined relationship between data and the commodification of gender and sexual identities. When he emphasizes that "data from Peru is urgently needed," it is because Peru has a large number of the types of people who are understood to be *most* at-risk. Understandings of risk, ways to measure it, and its worth in the broader political economy are bundled together, and thus data from MSM and transgender women are the commodity. The commodification of these data occurs as a process: converting certain people who are categorized as most at-risk into research participants, research participants into human subjects, and finally human subjects into extracted risk data. In the local Peruvian context, economies surrounding clinical research constitutes a form of labor that accrues both material and affective value. However, it is in the circulation of these data from Peruvian human subjects through transnational circuits of scientific knowledge that they can be leveraged for the promise of future economic gain.

Data arbitrage occurs in the extraction, trading, and selling of these data on a global market, data that are then transformed into scientific knowledge to advance understandings of the

HIV epidemic and biomedical prevention strategies for those most at risk. Unfortunately, all too frequently the production of this type of scientific knowledge functions to fuel the research industry rather than to employ tangible prevention efforts. Said differently, research begets more research, not prevention. For example, when asked about the HIV prevention research industry, Joaquín, a Peruvian MSM peer-recruiter and previous research participant, responded, “Where does all this data go? Why are we collecting more and more data? All I know is that this data isn’t changing the conditions for gay men and *travesti* here... but researchers keep getting more money” (Joaquín, interviewed September 2017). To answer his rhetorical questions, these data are transformed into scientific knowledge that circulates in and beyond Peru. Most commonly, they are analyzed for peer-reviewed manuscripts, and serve as the formative data for global North investigators’ next grant proposal.

Significantly, it is not just data generated from the bioeconomy of blood and tissue that holds value. Rather, these data implicate gender and sexual identities through a unique framing of risk as linked to prevention. In the contemporary HIV industry, the value in these data is about more than risk; it is about risky populations, which are defined and utilized to market a particular kind of concentrated epidemic. It is the epidemiology of the disease in this context and in this historical moment that is sold as commensurable with the global North research industry. And in this bioeconomy, risky populations—namely, MSM and transgender women—are conceptualized in specific ways and leveraged according to those classifications.

A conversation I had with Juan, a gay-identified Peruvian field worker, poignantly illustrates this point, describing the distinctions that HIV researchers make between gay men and other MSM.

Juan: I recruit MSM but I am not an MSM. I am gay and I am part of the gay community.

Amaya: So, if MSM stands for “men who have sex with men,” are you saying that you are recruiting men who are having sex with other men but do not necessarily identify as gay?

Juan: No. It doesn't matter how they identify. I often recruit men who identify as gay and bisexual, as well as men who identify as MSM or men who tell me that they are heterosexual. It is not about their identity, but their behavior. What matters is that they are at-risk for HIV. Being at-risk for HIV is why they are recruited to participate in these studies.

Amaya: When you say “at-risk for HIV,” what do you mean?

Juan: I mean that they have a lot of sex with other men, they are not using condoms, they don't have money for routine HIV tests, or even condoms, and they are not talking to their partners about their risk. Not all gay men are MSM... MSM are the men who are sex workers and come from the poorest areas of Lima. They are the ones who do not know how one gets HIV or what to do if you have HIV... Studies are interested in MSM, not in people like me or my friends.

(Juan, interviewed September 2017)

As Juan notes, engaging in sex work, living in poverty, and having limited education and access to HIV prevention and care are key characteristics that not only put people at risk for HIV, but are also core attributes in defining MSM as a research category. Moreover, while “transgender,” unlike MSM, exists as a term beyond the scope of HIV research, it takes on particular meanings and associations within understandings of HIV risk. For example, Luz, a transgender peer-promoter said, “I am trans but I am not the trans who participate in these studies. I have a steady partner. I do not live a crazy life like other *travesti* on the street. They are the ones at risk for HIV” (Luz, interviewed September 2017). In this way, the complex realities related to social class and hierarchical structures of marginalization—factors that shape HIV vulnerability—are embedded within these biomedical identity categories. Although these conceptualizations of “MSM” and “transgender women” remain unacknowledged, on the ground it is clear that research efforts are focused on individuals experiencing heightened social suffering and economic marginalization. Even so, the Peruvian epidemic is not sold as being about endemic

poverty, as in frequent characterizations of HIV/AIDS in Africa (Fox, 2012). Rather, it is marketed as a concentrated epidemic that disproportionately affects people of diverse genders and sexualities.

As I witnessed in Peru, HIV biomedical prevention research uses “MSM” and “trans” as shorthand proxies to denote certain most at-risk populations. This practice, versus using terms such as *gay*, *flete*, *travesti*, etc., works to inhibit sustained attention to the complex realities (i.e., poverty, lack of access to healthcare) that make people within these categories vulnerable to HIV. By inscribing these social complexities that pattern HIV vulnerability onto the identity itself, they are rendered inactionable. Thus, the very research that aims to ameliorate HIV among those most at-risk utilizes a process that unintentionally heightens vulnerability. For example, many studies emphasize testing therapeutic technologies (e.g., PrEP), yet such technologies generally remain unavailable in-country outside of research contexts. In this way, this research focus distracts from addressing structural solutions that would render condoms and HIV tests economically and socially accessible. This uncomfortable tension and paradox is central to contemporary HIV prevention research.

The story of extractive data practices traded in a global economy is not unique to HIV, but rather a key part of the reality of offshore clinical research more broadly. However, the Peruvian case study demonstrates the particular role of risk data in the 4th decade of the HIV industry’s focus on prevention. It is these data that are being arbitrated and that fuel a growth industry around detailing risk and testing biomedical HIV prevention strategies among individuals categorized as MSM and transgender women in Peru—a trend initiated by the global launch of iPrEx (2007-2011) and its extension study, iPrEx OLE (2011-2012). Indeed, most of the scientists and study staff I met while observing ongoing HIV prevention clinical trials noted

iPrEx as an important historical moment marking an explosion of research focused on people of diverse genders and sexualities. For example, as we waited for transwomen participants to arrive for their scheduled study visits, Joaquín, a peer-recruiter for more than a decade, told me, “Post-iPrEx things changed... There were more and more studies. Now it seems as though everyone is either trying to recruit you to participate or already participating in a study.” Since moving to Lima in 2009—when iPrEx had concluded but iPrEx OLE was just ramping up—I noticed this same thing, particularly an increasing focus on transgender women within HIV prevention research.

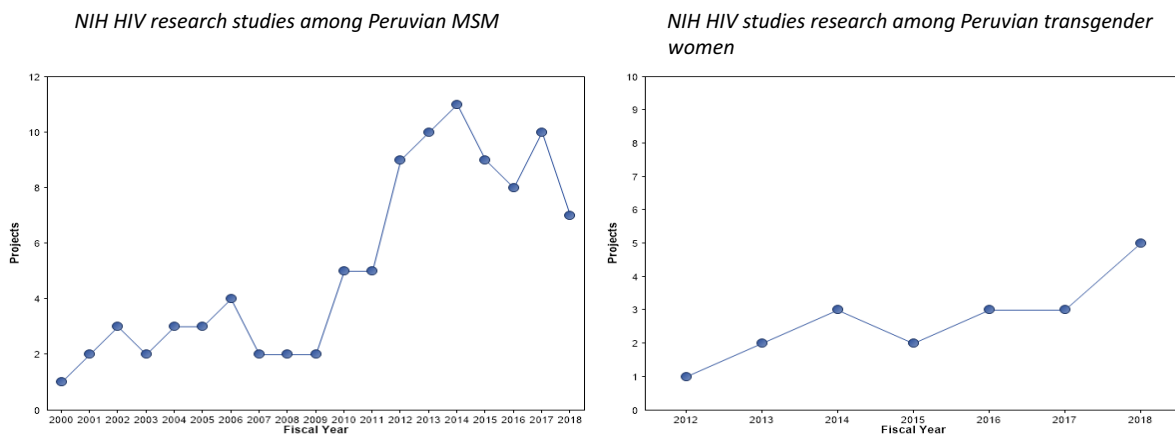
iPrEx was the first transnational clinical trial testing PrEP, and still one of the costliest (J. Cohen, 2010). As the first proof-of-concept study showing PrEP’s efficacy as a therapeutic HIV prevention technology, iPrEx sparked significant changes in both policy (i.e., WHO guidelines, FDA, CDC, etc.) and scientific actions (i.e., “real-world” follow-up assessments, such as iPrEx OLE). Notably, the study was only conducted with people categorized as MSM, a scientific category that at the time included transgender women. As such, iPrEx not only ushered in a new era of PrEP as the leading HIV prevention tool, but also of intensified focus on people of diverse genders and sexualities as a “prevention” population at heightened risk for HIV.

However, it is important to note that while iPrEx represents a watershed moment globally, its origins and impact hold unique relevance in the Peruvian context. iPrEx—both the study’s design and its overall impact—is particularly intertwined with the Peruvian HIV research enterprise, as the initial plan was to exclusively conduct it in Peru. While the study expanded to include sites in Brazil, Thailand, South Africa, and the United States, over half of the study sample originated in Peru (Grant et al., 2010). This is not surprising; given the prominence of US-trained Peruvian physician-researchers and number of experienced peer recruiters, Peru had

the research capacity and infrastructure to carry out complex protocols. Furthermore, the epidemiology of the HIV epidemic in Peru had demonstrated a concentration among MSM (Bastos et al., 2008; Tabet et al., 2002). iPrEx profoundly changed the research climate in Peru, transforming a site that received small to mid-scale HIV science grants funded by the global North into an epicenter of HIV prevention research conducted on MSM and transgender women.

Joaquín’s observation about the surge in research reflects the injection of global North funding to assess HIV-related risk factors among MSM and transgender women in Peru. For example, the National Institutes of Health reports a steady increase in the number of funded projects on HIV risk among MSM and transgender women (see Figure 2). It is important to note that although the first recorded NIH-funded study on transgender women was not until 2013, this does not mean that transgender women were previously omitted from research. Rather, it reflects that “transgender” was not used in project titles, descriptions, or abstracts, and that all prior studies classified transgender women (and the biological material and behavioral data they collected from them) under the category MSM. Thus, 2013 is a significant historical marker recognizing “transgender women” as a biomedical risk category within the Peruvian HIV prevention agenda.

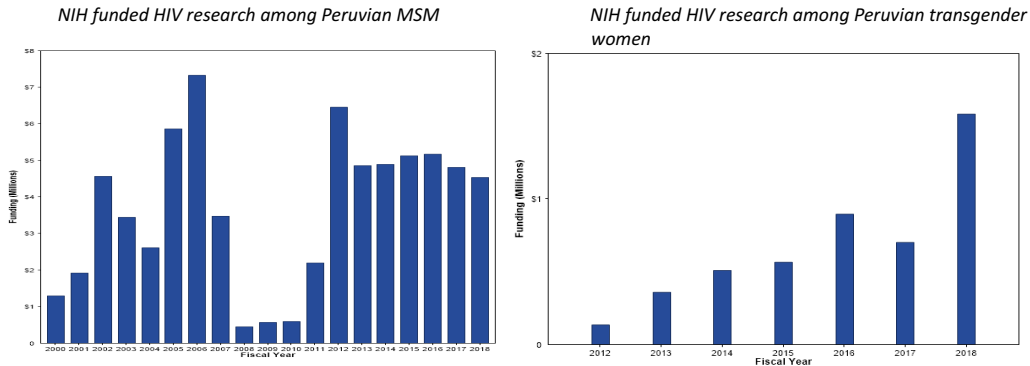
Figure 2: NIH funded studies among MSM and transgender women in Peru per fiscal year (2000-2018)



When assessing the increase in the number of studies conducted (see Figure 2), it is important to remember that there is overlap among them, as these studies last between three and five years. In 2013, for example, there were ten concurrent studies assessing MSM and transgender women. In addition, compared to the growth of research studies, funding profiles tell a slightly different story (see Figure 3). Noticeably, after recovering from the effects of the 2008 global economic recession, the average sum of NIH dollars post-2011 was about \$1.3 million USD. While funding flows to Peru increased prior to the initiation of iPrEx, what is unique about Peru's status post-iPrEx, and supported by the NIH reporting data, is the boom of research on MSM and transgender women, reflected in both funding dollars and the growth of individual research projects. What can be garnered even from partial data¹⁹ is that Peru represents a booming local research market, structured to evolve in line with broader demands and politics of the global HIV industry: an economy focused on collecting biological (e.g., blood, tissue samples, etc.) and behavioral (e.g., sexual practices, etc.) risk data from individuals categorized as MSM and transgender.

¹⁹ As highlighted in Chapter 2, publicly reported NIH funding is often misleading, as the largest recipients of funding are most commonly US institutions conducting network studies (i.e., iPrEx), which limits the ability to trace funding to individual countries.

Figure 3: NIH total funding among MSM and transgender women in Peru per fiscal year (2000-2018)



As demonstrated in this section, gender and sexual identities are commodified within the HIV industry’s focus on prevention, representing an emergent form of capital unique to the 4th decade of this field. In Peru, iPrEx marks a turning point that formalized this phenomenon. Specific forms of data that chronicle and catalogue risk and risk behaviors—biological materials such as blood, as well as behavioral data from surveys—have particular value, transforming risk data on Peruvians classified as MSM and transgender into an asset when traded in the global HIV biomedical marketplace. This trade is not equal, but rather arbitrated, as data collected and created in Peru hold more value outside of the Peruvian context.

Although previous scholarship has chronicled the slippage between research and social identities (Thomann, 2016; Wentzell, 2015), here we see a clear stratification of gender and sexual identities pulled out from the umbrella category of at-risk populations. As the Peruvian case study illustrates, classification processes of gender and sexual identities and a focus on the *most* at-risk are strategically employed in ways that benefit researchers on the global market. Indeed, the HIV prevention paradigm that has emerged in the 4th decade of the epidemic has

made the health and well-being of queer bodies the newest object of scientific knowledge and regulation.

The next section details the ways that data extracted from Peru are reinterpreted and repackaged to accrue value in the form of publications and grants. For scientists, this serves as currency to establish expertise in the field and obtain funding to do more research. Moreover, in addition to the value of the data, specializing in MSM and transgender research has its own value. Analyzing the ways that researchers engage in social practices and performances to substantiate their expertise, the following section considers another dimension of the concept of value in the global HIV research economy.

Entrepreneurial Scientists

The commodification of gender and sexually diverse identities operates as a mechanism to access specific kinds of bodies and associated risk data for the HIV marketplace, but the categories themselves also hold tangible and intangible value. Thus, I argue that commodified identities can also be understood as an asset. Kean Birch (2012, 2016) explains that a commodity is something that is for sale, and an asset is the “transformation of something into property that yields an income stream”(Birch, 2016, p. 468). He further clarifies the difference between the two with an example: “An asset is something like music copyright, while a commodity is more like a CD or downloadable song” (Birch, 2016, p. 468). Additionally, while all assets are commodities, not all commodities are assets.

For researchers in the Peruvian context, trading risk data in both the local market and transnationally has created value in the form of scientific expertise based on *doing* research on MSM and transgender people. Claiming expertise on these most at-risk populations, as an MSM

and/or transgender researcher, emerges as a distinct asset that such researchers mobilize in pursuit of entrepreneurial aims; namely, the ability to acquire grants, which are instrumental to employment, and the promise of future grants. This section details the distinctive features, and inequities, of how this asset is created and claimed.

In July 2017, I spent time in a research clinic specializing in MSM and transgender HIV treatment and prevention research that was actively enrolling several HPTN/HVTN-funded trials and other NIH-funded studies. I met a group of fellow Americans that were conducting research in Lima, two students and their mentor. As we were introducing ourselves, I asked the students what types of researchers they were, prepared to hear distinctions based on training and background; for instance, medical doctor, epidemiologist, biostatistician, etc. I was surprised when one of the students, Emma, said, “I am a trans researcher,” when describing her dissertation project, thus distinguishing herself from the other student whose project involved only people classified as MSM.

When I asked Emma to clarify what she meant by “trans researcher,” the students’ mentor turned to me and responded, “Emma’s research addresses a very timely need... the HIV epidemiology of transgender women, to better understand what places them at a heightened risk for HIV.” “Oh, so you are an epidemiologist?” I queried. To this, Emma replied, “I am trained as an epidemiologist, my PhD is in Epi, but my expertise is in transgender health.” It is important to emphasize that Emma’s response did not describe her own gender identity, but solely her scientific expertise and research focus. It was striking that she claimed “trans” over other scholarly identities, such as epidemiologist, Latin Americanist, etc. While I had heard both American and Peruvian scientists refer to themselves as “MSM researchers” in other interviews, this was the first time I had heard “trans” claimed as a category to demarcate scientific expertise.

Of course, the task of completing a dissertation and becoming a scientist entails gaining and demonstrating expertise, but my conversation with Emma and her mentor highlights that scientific categories denoting at-risk populations themselves hold value. This is not necessarily a new phenomenon, as scientists claiming to be “MSM researchers” demonstrates. However, those individuals who professionally characterized themselves this way generally also personally identified as gay. In fact, as mentioned in Chapter 2, many of the leading scientists with expertise in MSM research cite being gay as their impetus for studying HIV among other gay men, both in Peru and the US. Thus, the leading experts in the field (e.g., Jorge Sánchez and Carlos Cáceres) were openly gay men. In contrast, Emma’s response demonstrates that claiming to be an “MSM” or “trans” researcher is no longer about personal identity, but about leveraging scientific expertise *about* an identity.

But simply claiming expertise is not sufficient to become an expert. Rather, this claim needs to be supported by measureable criteria. As Collins and Evans outline, a mixture of credentials (i.e., diplomas, training), track record (i.e., publications, grant success record), and experience “provide externally visible indicators of expertise” (Collins & Evans, 2007, p. 70). The conversation with Emma and her mentor shows that training as an epidemiologist is part of the criteria for being a “trans researcher,” and the other components—track record and experience—will be developed during her doctoral work in Peru.

However, although Emma and other researchers’ track records will be based on their experiences, there is also a much larger human and material infrastructure built and carried out in Peru that enables scientists to claim expert status. This infrastructure includes a large local staff engaged in years of participant recruitment, strategies to maintain participation despite lengthy surveys and invasive repeat biomedical exams, the challenge of conducting HIV counseling,

attempts to help HIV positive participants obtain treatment from the unstable Ministry of Health, and numerous medical, organizational, administrative protocols regarding study drugs and the continual task of data collection.²⁰ Yet it is not through managing this dense and complex infrastructure that scientists establish expertise. Instead, they translate the data that results from study staff's substantial labor into peer-reviewed publications and additional funding that primarily benefit researchers and elite universities in the US. Their work is then valued and exchanged among scientists at a global-level as currency and revenue-generating assets that indicate ownership and expertise.

Authorship on peer-reviewed publications is an important component in transforming commodified identities into risk data and risk data into assets. During my two years of observing and participating in three biomedical HIV prevention studies focused on human subjects classified as MSM and transgender women, the discussions of authorship were too numerous to count. Indeed, Dr. Paulson, a US principal investigator, jokingly referred to the process as “trying to create a seating chart for an Italian wedding” (Dr. Paulson, interviewed May 2017).

Implicit in this metaphor are the complications that arise due to the large number of authors, tumultuous relationships and politics of authorship placement, and the work involved in trying to appease everyone, similar to the stereotype of designing seating arrangements for weddings. Authorship and author order on manuscripts and abstracts for conferences are crucial to convey expertise and claim ownership of these risk data. In the public health field, the first spot in a list of authors is most coveted, followed by the last spot, which is reserved for the senior mentor. Although debated, the second author position in quantitative manuscripts

²⁰ See Chapter 4 for more on the research assembly line.

typically goes to the analyst. Manuscripts operate as the ultimate record keeper of a scholar's scientific reach, and they are essential to demonstrate expertise and acquire grants.

However, this path to establishing expertise, including the value of publications and grants, is understood to exclusively apply to investigators from the global North—namely, the US—and only the most senior of Peruvian collaborators. For example, Juancito, a Peruvian project coordinator with more than a decade of experience with HIV prevention research, has a Peruvian medical degree and a US master's degree in epidemiology. When I asked him about his perspective on authorship and the value of publications, he mentioned the challenges specific to Peruvian investigators, the most obvious being the difficulty of publishing in English, and explained that his job is dependent on another scientist's ability to secure funding. Significantly, he also asserted, “Publications don't really help me keep a job. They would be good, but I will never be a leader of HIV research in Peru. That role is reserved for US investigators and Jorge and Javier [Dr. Jorge Sánchez and Dr. Javier Lama]” (Juancito, interviewed February 2018).

In stark contrast, Ken, a third-year US medical student living in Peru as an NIH Fogarty Fellow, described the aims of his research year abroad: “[To] conduct a study and publish at least one first-author paper.” In his view, “This year is crucial for me to show I can do MSM HIV research in a global setting. After residency, I want to apply for a K [grant]²¹ to continue my research in Peru... Without publications, it will be difficult for me to get a grant and continue to do global health research” (Ken, interviewed August 2017). Comparing Juancito and Ken's experiences not only illustrates varying perspectives on the importance of publications, but also

²¹ The “K grant” refers to an opportunity within the NIH Career Development Programs. It is a five-year grant of approximately \$54,000 USD per year that is meant to introduce highly trained scientists into research, and place them on the pathway to researcher independence—meaning, to obtain future grants.

demonstrates that career advancement opportunities between Peruvian and American researchers—and between global North and global South scholars—are simply unequal.

Among those able to access this pathway, there is tremendous social and professional value in claiming expertise and ownership of HIV prevention research among people categorized as MSM and transgender, which includes the value of the categories themselves. An interview with Dr. Galvez, a Peruvian physician-scientist trained in epidemiology at a US institution, illustrates this point. He received NIH funding for training and was invited to an NIH health symposium in Bethesda, Maryland for all global trainees to learn about NIH-sponsored funding mechanisms for global health research. “I was attending a presentation titled ‘How to Be a Global Health Star,’ can you believe it? ‘How to Be a Global Health Star!’” he emphasized. He continued, “I don’t want to be a star, I just want to get funding so that I don’t always have to work for Americans.” Moreover, it struck Dr. Galvez that HIV risk and vulnerable populations were being exploited to gain “a weird, almost rock star status as a global health researcher” (Dr. Galvez, interviewed July 2017).

Dr. Galvez started working in transgender health in Peru because a close transgender colleague informed him of the distinct realities and needs for transgender women compared to MSM. However, he noted, “As I became known as a trans researcher, more US colleagues wanted to work with me, and I was invited to participate in projects not only in the US but across Latin America” (Dr. Galvez, interviewed July 2017). Referring back to the distinction between a commodity and an asset, this quote brings to the fore the capitalization of knowledge as an intangible asset that not only demonstrates economic and symbolic potential, but is also a tradable resource on the global HIV marketplace. Indeed, considering the 2017 NIH special funding call on transgender health (National Institute of Allergy and Infectious Diseases, 2017),

claiming expertise on gender non-binary populations is quite strategic, as doing so is clearly marked as an asset with revenue-generating potential.

Additionally, a conversation with María, a transgender woman who previously worked as a recruiter for iPrEx but now dedicates her time to activism, highlights that asserting expertise on gender and sexually diverse communities is a way to establish a lucrative research brand. She explained, “Researchers call themselves MSM or trans researchers because it is strategic. It is their brand. They act as though this work can’t be done without them. They are wrong. Let’s be clear, this work can’t be done without the involvement of the community” (María, interviewed April 2018). As María’s quote further illustrates, claiming scientific expertise by conducting research on MSM and transgender women is a way that researchers position themselves as indispensable for this type of biomedical research, and thus maintain their own involvement. Indeed, as shown throughout this section, what is unique about MSM and transgender categories in HIV prevention research is that they are not only leveraged as mechanisms to access risk data, but also that the categories themselves hold symbolic value, as assets in the form of scientific knowledge and expertise.

On Being a Commodified Identity

Claiming membership within the categories of MSM and transgender women also holds specific value both as a commodity and as an asset for Peruvian gender and sexually diverse communities, as they strive to broker multiple kinds of access to meet their unique health needs. Indeed, people generally seek to leverage their position in whatever ways they can within their circumstances. What is troubling is the limited non-research infrastructure available to provide healthcare to people classified as MSM and transgender, and the precarious nature of the

opportunities to which they do have access. In this context of temporary healthcare and economic instability, this section details how people within these categories make the most out of the political economy of HIV prevention research.

While tensions exist between definitions and membership boundaries regarding the terms MSM and transgender, self-identification with these categories can provide value in three specific ways. The first is access to needed healthcare, albeit temporary, and other incentives through participation as a research subject. Secondly, knowledge of both the intricacies of gender and sexually diverse communities and the research process provides job opportunities in the formal economy of the HIV prevention research industry. And thirdly, flows of HIV science funding and targeted research on gender and sexuality diverse communities have provided strategic, yet bounded, opportunities for community mobilization. This is complicated, and claiming a biomedical identity is neither all good nor all bad. Rather, living as a marginalized person requires a delicate balance in order to survive in an oppressive society, and as a human subject in a research environment that exploits existing societal inequalities.

I spent an especially challenging afternoon attempting to locate transwomen research subjects with two peer recruiters, Yasmin and Yaiza, in February 2017. It was the middle of summer and a particularly hot day. Lima sits on the northern tip of the Atacama Desert, receiving virtually no rainfall (Climate data, Lima, Peru (n.d.)), and its air quality is ranked the second-worst in South America, after Santa Gertrudes, Brazil (“Cities with the worst air quality in South America,” n.d.). The heat exacerbated the dust and smog, and made the six hours we spent going into brothels and navigating city streets even more difficult. While these work conditions are common during recruitment and outreach in the summer months, this was not a traditional recruitment visit. Instead of recruiting transwomen to participate in studies or to remain engaged

through outreach efforts, Yasmin, Yaiza, and I were trying to track down participants who had enrolled but dropped out or stopped showing up for study visits at the clinic. We did not have a successful day. We had only been able to locate one transgender woman on our list, and she clearly described study fatigue and disinterest in continuing.

I had worked with Yasmin before and we knew each other personally, but this was my first time working with Yaiza. We decided to go out for a beer and debrief, and I welcomed the opportunity to connect over drinks. Our night out also provided a window into the tensions and burdens of being part of a gender-diverse community, and leveraging this membership for employment purposes. For example:

Yaiza: Amaya, you saw today how difficult it is to do the work we do. It takes a special *travesti*, one who is known in the community and respected, like Yasmin. She is a *madre* to many *chicas* in Lima...²²

Yasmin: Many trans[women] know me and they trust me. They trust that if I tell them to participate that these studies are important and good for them... But often it is too difficult to continue to be part of these studies. That was the problem with Celia [the transwoman we had spoken to that day], it was too hard to get to the clinic and the wait time too long... No matter how important I tell her it is to go and to stay on PrEP, if it is too difficult she won't go back. This is the way it is.

Amaya: ...This is incredibly difficult work and even more challenging because you have close relationships with many of the people you are recruiting to participate. Why do you choose to do it?

Yasmin: I believe that we all need to do things to support our community. It is hard to be trans in Lima. There are few doctors who will treat you with respect or understand our health issues... Most see us as dirty and as *putas*. These studies give *mujeres trans* access to healthcare.

(Yasmin and Yaiza, interviewed February 2017)

Conversations with study participants mirrored Yasmin's perspective that studies provide needed healthcare. In fact, several voiced that they believe that they are able to obtain better care through

²² *Madre* translates directly as "mother," and refers to one's position in the transwomen community as a leader and role model.

studies than through Lima's other healthcare options. Julio, a self-identified gay man who had participated in a total of four studies, told me,

Immensa, Impacta, Via Libre [the main research clinics in Lima] provide the newest HIV testing and treatment technology. I know that by being part of research I have access to the best science has to offer. When you go to MINSA [Ministry of Health] clinics, who knows what type of test you will get or if the doctors even have the training to administer HIV treatment, one hundred percent [of doctors]... don't have the training to give PrEP. (Julio, interviewed August 2018).

Other participants and study recruiters echoed Julio's point: that access to free HIV testing is a known benefit of participating in research studies, one that peer-recruiters frequently leverage when trying to entice community members to take part.

For example, in June 2017, I spent a few weeks shadowing Jana, a trans peer recruiter who was actively recruiting transgender women for two HIV clinical trials. One night, we were in a plaza in the center of Lima known for sex work, trying to recruit transfeminine Peruvians. Jana knew the majority of these women, so recruitment was pretty informal. One woman, Lola, approached us and said, "Jana, I need to get an HIV test, it's been in awhile." Jana replied, "Great, go to Impacta [the research clinic that was enrolling study participants] and say you are interested in this study." Lola clarified, "No, I don't want to be part of the study. I just need a test." In response, Jana advised, "Pretend you do, get your test, get your incentive, and then don't go back" (Jana and Lola, observation June 2017).

This interaction between Jana and Lola demonstrates the value of claiming these biomedical categories, even temporarily, to access HIV tests. In Lima, there is public funding for sex workers and for people categorized as MSM to get free HIV tests at certain public clinics, but not for transgender women, even those who engage in transactional sex practices. As a result, participation in research can provide needed healthcare that can otherwise be difficult and costly to obtain, as in Lola's case. In addition, as Julio pointed out, although free health services may be

available for some people who are categorized as at-risk, the testing associated with research studies is considered more valuable due to the perception of quality.

Accessing the services provided by HIV prevention research is an important benefit of participating. Yet there are inequities regarding who receives care. María, a transgender peer-recruiter for a study assessing whether hormone provision improves routine engagement with HIV treatment and prevention among transgender women, explained, “Yes, yes, this study gives trans hormones. Participants don’t have to pay for them, and a doctor gives it to them, which is so important, but they aren’t free. To get hormones you need to routinely come all the way to Impacta and get tested, and get tested frequently” (María, interviewed April 2018). María’s point illustrates the transactional nature of these studies, which complicates understandings of volunteerism in participation with implicit questions of coercion. Participants benefit from access to testing and hormones, and thus participation holds a tangible value for them. However, what often remains unacknowledged is the invisible labor, cost, and time that make continual clinic visits possible—factors that, for some potential participants, simply outweigh the advantages. As María argues, these services “aren’t free.”

According to many transgender women, an additional drawback to participating in HIV prevention research is being treated like a guinea pig. On the ground, more transwomen than gay men voiced this sentiment, and chose not to participate in clinical trials because of it. This was particularly common with therapeutic prevention technologies, such as PrEP, as transwomen expressed suspicion and apprehension regarding the current emphasis on transgender women as a “key population” for HIV prevention efforts. For example, Karla, a former iPrEx participant who declined participation in the two clinical trials I was observing, stated, “I would not take it [PrEP] because it isn’t proven one hundred percent effective. I would take it [PrEP] if it were for

everyone, not just for transgender women. Because there shouldn't necessarily be a drug for *travesti* women, it should be for all, for heterosexuals, for everyone" (Karla, interviewed July 2018).

Luz, a peer-recruiter for these studies, similarly echoed, "Why are we [transgender women] being used like guinea pigs, every single one of us, to test something that hasn't been fully confirmed?" (Luz, interviewed July 2018). This notion of exploitation through continual testing, probing, and, in certain instances, exposure to unknown drugs, underlies the nature of HIV prevention research as an extractive enterprise. Even so, there exists a tangible value to the HIV services that the research studies provide, which frequently outweighs these negative associations.

Moreover, participation in HIV prevention studies can constitute formal and informal forms of employment. This demonstrates another aspect of how the commodification of gender and sexual identities can provide value to those claiming membership within biomedical categories. I became aware of the explicit value and labor of research participation when observing recruiters trying to enlist MSM and transgender women. In July 2017, I joined Carlos at around 11:00 p.m. in a public plaza in the center of Lima, which after dark functions as a popular venue for sex work. Carlos selectively approached individuals based on his perception of how risky and potentially interested they would be in participating. Notably, if they seemed even moderately interested, he emphasized several times that they would be remunerated for their participation with economic incentives. Leveraging incentives is a common tactic among peer recruiters, but only illustrates part of the complex value structure embedded within research participation.²³

²³ The following chapter offers further details on the social processes surrounding the political economy of HIV prevention research, and the work of being a human subject.

A second interwoven aspect of the value derived from claiming membership in and knowledge of the categories MSM and transgender women is the possibility of formal employment. For example, Yasmin, a clinical trial staff member and well known trans *madre*, explained, “I was hired as the leader of Mujeres because I know first-hand the risks we [transwomen] put ourselves in daily to survive, I understand what PrEP is and why it is a benefit to our community. I have also been trained in research, so I know the importance of these data” (Yasmin, interviewed February 2017). What is perhaps most striking about Yasmin’s quote is that her duality is a requirement for employment. Her occupational success in HIV prevention research is contingent upon both a deep knowledge of the active processes needed for research and her status as a well-known and connected transgender woman.

Gender identity—specifically, the understanding and acceptance of it within a global North rubric that positions “transgender” as an umbrella category—emerges as a requirement for this type of employment. Indeed, I observed this first-hand in February 2017 while attending a Mujeres staff meeting. As Maite, a Mujeres staff member, announced to the group but mainly directed to Yasmin, “Several of the *travesti* coming in don’t understand the word transgender and don’t identify as transgender. This has become a problem on the surveys since they are leaving this question blank, and Dr. Smith has emailed me twice now about missing data on the surveys.” To this, Yasmin responded, “Tell them that *travesti* is the same thing as transgender and that these surveys were written by *gringos*. Plus, if she wants to continue in the study, continue getting PrEP, and continue getting money, she needs to fill out the survey completely.”

This interaction demonstrates the active process of introducing biomedical lexicon into community discourse, and the politics behind it. Being categorized as MSM and/or transgender by study staff (including but not limited to peer-recruiters) is an eligibility requirement for

participation in HIV prevention studies, whether or not the person identifies as such. The categories are considered more significant than risk behaviors. This means that people with identical sexual behaviors—for example, a heterosexual man, transgender man, and cisgender woman who all have multiple partners, exhibit low to no condom use, etc., and thus all have a similar risk of acquiring HIV—would not be eligible to participate in these studies. Furthermore, this example highlights the uncomfortable tension within *gringo*-designed research that lacks contextual relevance, and as a result leads us to question not only the value of the data collected but the coercive nature of the process itself.²⁴

However, commercial opportunities within this research enterprise do not emerge for everyone who is well connected and trained in research. Rather, employment is only possible for those who meet these criteria *and* conform to the industry’s classed assumptions about types of gender and sexually diverse people. Carlos, a peer-recruiter with over a decade of experience both working and participating in biomedical research, explained these distinctions:

Carlos: As a recruiter, I am gay. But when I am a participant in studies, I am an MSM.

Amaya: Can you tell me more about the difference between when you identify as gay versus MSM?

Carlos: I am always gay. I desire men, I only have sex with men. But when I work as a recruiter, I only get hired if it seems like I am stable... You have a bank account, you are able to hold a job... not partying all the time, not being promiscuous. You know, a stable gay man who knows the movement of the community in Lima but doesn’t participate [gently laughs]. But, if I want to be in these studies, I need to be an MSM. I need to show that I am at risk for HIV and thus qualify for the study.

Amaya: How do you demonstrate risk in order to qualify?

Carlos: All of these studies make you fill out an extremely long survey about sexual risk behavior. Typically, it asks about number of partners, how many times you have [had] unprotected sex, the last time you went to get an HIV test, used drugs and alcohol. If you have a stable partner and never go out, you don’t qualify. Studies want people who are at

²⁴ See Chapter 4 for a more detailed description of the challenges regarding agency in research participation.

risk. So when I want to be in a study, I am truthful that I like to have fun. But if I want a job, I pretend to be a saint.

(Carlos, interviewed March 2018)

It is important to interrogate the meanings embedded within the industry's perception of stability, such as socioeconomic status, and how they structure access to employment within the HIV prevention research economy. In order for gay and bisexual men to be employed, Carlos highlights the need to present themselves as knowledgeable about risk and risk behaviors, but not be "risky" themselves. Furthermore, tangible attributes that connote stability, such as being able to open and maintain a bank account, require a level of income that is often unavailable outside of a formal economy. Employment through transactional sex practices, for example, or even contract work, frequently do not necessitate that individuals save their earnings and/or use formal banking systems, nor do they facilitate such financial practices. But although these classed ideas inform the biomedical category MSM in ways intended to limit participants and employees to certain "types," Carlos's narrative shows a keen understanding of how to manage and benefit from the system.

It is slightly different for transgender women. For example, Luz reflected that she was hired as a recruiter because she was "dependable and presented well. It has taken me years to know how to dress and be a *travesti* so that I don't always get harassed when I go outside... I still get harassed, especially in *combis* [public buses], but not every time I leave my house like I used to" (Luz, interviewed July 2018). Here, Luz uses "presented well" to convey that she has the social and economic capital to not only dress professionally, but also to be read as a cisgender woman. Similarly, Elvira, a study participant noted, "In the future, when I am further transformed, I would love to be able to work as a recruiter. Something to get me off the street [street-based sex work] or to help me afford a better living situation. Now these [grabbing her

buttocks] are just injections, but I want to get implants. And I want to grow my hair longer” (Elvira, interviewed July 2018).

As both of these quotes reveal, for transgender women, visual features—especially the ability to “pass” as cisgender—are a significant means of conveying the dependability and professionalism necessary to secure employment in the research economy. While both Luz and Elvira self-identify as transgender women, Elvira recognizes her gender fluidity or non-binary appearance as an impediment to obtaining such a position. While she would be accepted as a study participant, she knows that she must be further “transformed” if she wants to pursue formal employment in research studies. Thus, while identifying as trans (or MSM) can provide financial and health benefits within the political economy of HIV prevention research, the value of these biomedical categories remains problematic, inequitable, and tenuous.

Finally, a third type of value emerges from the commodification of these identities in HIV prevention research. Beyond access to needed services and employment, even if only temporary, flows of HIV science funding and targeted research have also provided strategic, albeit bounded, opportunities for community mobilization. Literature has documented the rise and fall of gender and sexually diverse grassroots community organizations that are primarily reliant on Global Fund money, as well as international HIV money’s influence in shaping civil society (Amaya et al., 2014; Caceres et al., 2009; Parker, 2011). However, I demonstrate how flows of HIV science funding – both programmatic efforts and research initiatives—have also created space for collective action.

Two primary examples, with inverted stories, illustrate this point. The first is Fénix, a primarily gay community-based organization that began in 2007, unconnected to HIV research. However, due to economic instability, Fénix transformed into a recruitment and HIV treatment

and prevention research space around 2010. The second is Mujeres, a community-based organization run by transgender women, created in 2015 as a recruitment and retention center for a research study. After the study's conclusion in 2018, Mujeres has continued as a community-based meeting space without formal ties to clinical trials. Both Fénix and Mujeres provide illustrative examples of the kinds of community building that emerge due to HIV funding, and demonstrate the blurred lines between community activism and HIV research.

Today, Fénix is managed by a Peruvian psychologist and operation funds are directly linked to HIV clinical research. However, Fénix's initial aim was to create a grassroots community space for gay men's health and wellbeing apart from research, modeled on the San Francisco AIDS Foundation (SFAF) Magnet Clinic. A 2008 abstract submitted to the International AIDS Conference described Fénix (alongside Health4Men/PlayNice in Cape Town, South Africa) as having been created in line with SFAF's vision to provide:

A multi-year planning effort led by gay men sought to de-stigmatize sexual health and provide education that moved beyond an AIDS-based paradigm; integrate services; and instill men with a sense of ownership over their health vision. (Gibson et al., 2008)

According to one of Fénix's founding members and a US physician-researcher, Dr. Dover, SFAF actually provided the organization's initial seed funding, but Peruvian community members assumed all decision-making control and planning responsibility. When describing the rationale for starting Fénix, Dr. Dover stated:

There was a real need to create a community space dedicated to gay men's health that was apart from studies. While Immensa started Quinto Piso and Impacta had Casa Abierta, these community spaces were linked directly to research. And, as such, there was no way to distinguish what was research and what was community. (Dr. Dover, interviewed January 2018)

But although this may have been the initial intention, today Fénix is primarily a clinical research site. According to the current director, Pancho Hidalgo, “Fénix couldn’t survive as an activist organization. I am grateful that we were able to adapt and sustain ourselves through HIV research” (Pancho Hidalgo, interviewed August 2017). Thus, uniting community-based organizations with HIV research presents an opportunity structure that the community can leverage in order to support a type of activism that would otherwise be unsustainable. Indeed, Fénix’s evolution reflects a synergy between HIV activism and HIV-related research. In Hidalgo’s words:

The fact that Fénix is first and foremost a community-based organization strengthens how we do research with gay and bisexual men and, now, transgender women... The reality is that our community is suffering from HIV and the state does not provide adequate services. But research does. So here we are connecting people from our community to the services they need through research. (Pancho Hidalgo, interviewed August 2017).

But the synergy Hidalgo describes also has unresolved contradictions, primarily that spaces for LGBTQ activism are dominated by discussions and activities not only related to HIV, but also to enhancing HIV research practices. For example, in July 2018, I attended an Fénix community discussion held routinely on Wednesday nights with about six men in attendance. The main topic of conversation was infidelity and how to discuss monogamy with your partner. One person claimed that monogamy in the gay community is an illusion, arguing that words are fine but one needs to be true to themselves first. As an example, he disclosed that he had been in a stable “monogamous” relationship for six months, but nonetheless took PrEP as a precaution. This reference to PrEP spurred a discussion of biomedical prevention options and ways to access them through ongoing studies being held at Fénix. There were even recruiters present to offer such information. In this way, I observed that while Fénix is a community space, this weekly meeting was also a highly effective means of recruiting gay men for participation in ongoing HIV studies.

In contrast to Fénix, Mujeres emerged as a recruitment and retention center directly linked to two HIV biomedical prevention studies focused on transgender women. Yet, run by Peruvian transgender women, Mujeres quickly took on a life of its own. As part of the team of investigators that designed and conducted these studies, I have been part of Mujeres – both the research aspects and physical space for community mobilization – since its inception. During the three-year period of the study, Mujeres had the funding to rent a house specifically for community workshops (which were part of the study’s intervention). When Mujeres started in 2015, there were other transgender community-based/activist organizations (i.e., Red Trans Peru), but Mujeres was the only one with such a dedicated space. Additionally and importantly, the four transgender women hired as study staff had the rare responsibility of managing a research budget related to community activity.

Interested in creating a space that reflected community needs beyond the studies, Mujeres staff utilized the budget allotted for meeting snacks, such as chips and sodas, to buy groceries. Then, on Saturday afternoons, they would invite study participants and other friends to get together and jointly cook a meal. I attended several of these events early on, and there were no planned discussions; rather, Mujeres simply served as a communal gathering space. However, about six months after they began, the success of these events reached study leadership, and they were strategically co-opted to retain study participants. For example, if a participant had not attended several workshops or clinic visits, a Mujeres staff member would call and personally invite her to the Saturday gatherings. If she attended, they would use that opportunity to re-engage her in study procedures.

At the end of 2017, Mujeres began to garner recognition in Lima and globally as a transgender community-based organization apart from HIV prevention research affiliations

(Brand, 2017). Recognizing this, Mujeres director, Yasmin Costas, officially incorporated Mujeres as an NGO with the explicit intent of maintaining the organization after the anticipated completion of the studies at the end of 2018. Costas made it clear in our discussions that she was utilizing Mujeres as a unique opportunity to advocate for the needs of transgender women including and beyond HIV care. In her words:

Through Mujeres, we have become a collective and together we have power... I always tell people that whether or not they want to be part of the study, they can always be part of Mujeres. We do more than research... [For example,] one of our members told us about how she was discriminated [against when] entering a disco. We got together and filed an official denunciation with the police. (Yasmin Costas, interviewed June 2018)

Despite Costas's efforts, when the study ended, so did the funding for Mujeres. However, Mujeres continues today, with meetings held at a member's house in the center of Lima. While encouraging, the organization's link to research continues nevertheless, as former staff members have been hired as recruiters for other studies, and in this way Mujeres continues to be utilized as a recruitment and retention space.

This section draws attention to the complicated benefits of claiming membership within the categories of MSM and transgender women, and how Peruvian gender and sexually diverse communities leverage the value of these identities in and beyond HIV research settings. Goods things can come of being classified as MSM and/or transgender in the HIV prevention marketplace, but they are nonetheless precarious due to the temporary nature of the studies. Additionally, as these examples demonstrate, we need to be critically aware that any visibility and benefits are afforded through a medicalized space that fosters dependence on the larger research process.

Conclusion

In the context of the 4th decade of the HIV epidemic with its explicit focus on biomedical prevention and at-risk populations, people of diverse gender and sexual identities must be understood in relation to the value that can be derived from them within the research process. For better or for worse, the growth of HIV biomedical prevention efforts has not only structured contemporary science and associated economic ventures, but also the individual biographies of people who form part of the communities most impacted by HIV and HIV research initiatives. Through an analysis of the different economic value systems associated with doing research on MSM and transgender women, and with being involved in research as a person within these categories, this chapter draws attention to the uncomfortable entanglement between people, health, and capitalism at the center of HIV science.

The Peruvian boom in collecting data from people categorized as most at-risk—namely, MSM and transgender women—grew post-iPrEx and paralleled broader trends in global HIV research efforts. On the ground, my observations of ongoing clinical trials that developed out of this boom, and conversations with scientists, research staff, and research participants demonstrate that within this value system, the compensation of human subjects is quite uneven, disproportionately benefitting researchers. While participants do receive necessary medical services, albeit temporarily, the risk data they provide—materials ranging from blood to behavioral surveys—are both a commodity and an asset that fuel the growth of the HIV biomedical marketplace in Peru and globally. Moreover, these data offer global North researchers entrepreneurial opportunities to publish, secure additional research funding, and become recognized for their expertise in working with MSM and transgender populations.

Indeed, the commodification of these identities produces an exploitable research population to sustain the HIV biomedical economy.

Further, the use of MSM and transgender women as biomedical categories is more than a system of classification based on gender and sexuality or a surveillance technology for differentiating and counting people. These categories are powerful tools through which scientists not only collect and trade data (commodities) on a global scale, but also claim expertise (assets) about certain bodies and identities for the purposes of publishing, obtaining funding, and expanding their own dominance in the field. Although this process informs scientific knowledge and the development of innovative technology to prevent HIV, it is specifically the promise of future research that, combined with understandings of risk, further fuels the value of data extraction on gender and sexual identities in HIV prevention research.

This chapter interrogated the concept of value by detailing the social life of risk data and its relationship to the circulation of capital within local and global HIV markets. Building on this argument, the following chapter dives into the micro-economies that commodify people of diverse genders and sexualities at each step of the research process, ultimately transforming people into participants, laborers, and de-humanized data. By doing so, I illustrate the often invisible multiple components that build on each other to create a complete research study. What emerges is a description of an intricate ecosystem comprised of researchers, participants, community-based promoters, and clinical study staff through which compensation, value, and work shape interactions throughout the research process.

Chapter 4

The Research Enterprise

One afternoon, in March 2018, while trying to interview transgender women who had been recruited and enrolled to participate in a clinical trial assessing adherence to PrEP,²⁵ I found myself in a brothel in the historic center of Lima. I was working alongside Yasmin, a colleague and leader in the trans community hired as an independent contractor for the study, who was assisting me in locating transwomen who, in research terms, were considered “lost to follow-up” or “study drop-outs.” We were told that many of the transwomen we were looking for currently resided in the same location. As we approached the address we had been given, Yasmin explained to me that this area was a well-known “mixed” sex work venue. She meant that both cisgender women and transgender women worked within this space, renting small, damp, cramped rooms within the grandiose walls visible from the street.

Knowledgeable about the local context, Yasmin explained that this was a unique situation, as other sex work venues in Lima, including street-based sex work, have marked and divided territories for cisgender women, transgender women, and cisgender men. From the street, cars and people were sparse but the avenue was lined with towering forty-five-foot walls showcasing the Spanish colonial influences that have shaped Limeño history, architecture, and culture. The stark contrast between the newly painted towering walls and the crumbling living

²⁵ PrEPTrans was funded by NIH as an intervention development grant and, as such, is comprised of three parts. The first was a formative clinical trial to assess PrEP’s acceptability among transgender women through qualitative methodologies. The second was a pilot behavioral intervention conducted about transwomen community leaders to see whether fortifying social networks could improve adherence to PrEP. The final stage was a cluster randomized trial, dividing Lima into three geographic areas: North, Center, and South. Each geographic area had two cohorts, one randomized to intervention and one to control. All PrEPTrans participants took the study drug, PrEP, but those randomized to intervention received community-led workshops and social media support (WhatsApp, Facebook) as well as access to peer promoters.

spaces hidden behind them speak to the greater reality of Lima's historic center: striking architecture in ruins, pervasive poverty amidst economic boom,²⁶ and the most marginalized of Peruvian society living within a declared UNESCO World heritage site (see Figure 4).

Figure 4: Living Conditions for Transgender Women in the Center of Lima



Photo courtesy of Sarah Mclean



Photo courtesy of Sarah Mclean



Photo courtesy of Daniella Villasana. Of note, this transwomen was not interviewed as part of the ethnographic fieldwork.

²⁶ Between 2002 and 2012, the Peruvian economy almost doubled in size and the gross domestic product (GPD) grew at an average annual rate of over 6 percent (IMF, 2013). Currently, less than 30 percent of Peruvians now live below the poverty line, and economic growth has been well above the Latin American average. Additionally, between 1997 and 2009, Peru's Gini coefficient fell from 0.53 to 0.49 (IMF, 2013).

While most of the building façades in Lima’s historic center are maintained to enhance tourist appeal – mainly those driving through the area on their way to the nearby famous Plaza de Armas and its surrounding basilicas – the neglect is nonetheless exposed by the shuttered windows and absent roofs. Stepping through one of these brightly painted façades, we were met by a cisgender woman ushering out two male clients and the pungent smell of dog excrement. Upon spotting us, the woman greeted Yasmin, who explained that we were there to see Marisol. In response, the woman nodded and told her dog not to bite us. (It didn’t then, but it nipped me hard as we left an hour or so later.)

Inside, the space was divided into a narrow hallway that led to several rooms that were rented out on a weekly basis for the purpose of sex work. Yasmin guided me to Marisol’s room and, before we knocked, explained that Marisol had made it through the four initial study visits (which included HIV testing and two individual counseling sessions) and had received a one-month supply of PrEP. After that, she never returned to the study clinic or responded to outreach from study staff.

Marisol invited us into her room as her client left, greeting Yasmin as “*madre*”, a sign of respect for Yasmin and her reputation as a leader and role model in the local community of transgender women. Leveraging this social capital, Yasmin introduced me as “a researcher who is a friend. You should feel comfortable telling her the truth, about why you aren’t taking the medicine”. Noting Marisol’s apparent disinterest in speaking with me, Yasmin added, “You will be paid 40 soles [the Peruvian currency] and the interview will only take thirty minutes.” I would later learn that while prices vary across Lima, in this area most transgender women make between 25 and 45 soles per sexual encounter, which lasts about five to ten minutes. My interview would take much longer for the same amount of money.

As Yasmin took her leave to go talk to other women in the house that she knew, Marisol closed the door and invited me to sit on a chair next to her full-sized bed. Marisol began to tidy the sheets and the room, her work/living space, from her last sexual encounter, before sitting back down to explain that she didn't have too much time to talk. At best, she was moderately interested in speaking with me, and made it clear that our conversation would be cut short if her next client arrived on time. From this initial interaction, it was evident that, in her view, this conversation was transactional (i.e., it was work) and that it was not a priority in comparison to the other labor she would engage in once her next client arrived. Furthermore, it was unclear whether her willingness to do the interview – slight as it was – was due to respect for Yasmin, the expected economic remuneration, because it was the easiest way to get rid of us, or a combination of all these factors.

However, the more we talked, Marisol's interest in the conversation grew, especially as she described why she thought HIV prevention tools like PrEP would be of use for transgender women who engaged in sex work. Referring to PrEP primarily as Truvada, its brand name, Marisol described it as “the little pill that was extra protection.” She proudly showed me where she kept the medicine bottle, in the top drawer of her dresser, closest to the bed, and repeated back to me some of the information she had learned about PrEP efficacy through the study's individual counseling sessions.

But while Marisol voiced a positive opinion about the need for PrEP as an HIV prevention option, she also said that she didn't take it. She explained that the study procedures were too burdensome. The clinic site was too far away, appointment times too early in the day (which conflicted with her work hours, typically from six o'clock at night until one or two in the morning), and the wait time at the clinic too long. However, she was storing the medication for

later use, just in case. She said, “I like the idea of PrEP, just not now. I am saving it for a later time... I know that the study will end and the drug, even if available, would be expensive, so I am keeping my bottle in case” (Marisol, interviewed March 2018).

I was surprised to learn from this response that Marisol acknowledged the temporary nature of the studies and the precariousness of the care she received through them. She recognized that while PrEP wasn't what she wanted at the moment, there was a strong possibility that she would be unable to obtain it in the future, outside the context of the study, and so she kept for later what she had access to now. She explained, “Perhaps some people could afford PrEP, but for us, *las travestis*, that wouldn't be a reality. We get our tests and condoms through studies. PrEP will be the same” (Marisol, interviewed March 2018). Our discussion about this study and others more broadly marked a shift in our conversation from Marisol's own experience to the potential impact of research on the larger trans community. In doing so, this illustrates that clinical research practices, like offering routine testing, condoms, and, importantly, economic incentives, structured how healthcare is constructed and obtained by transgender women in Lima.

My interview with Marisol was one in a set of interviews I conducted with transgender women as part of an evaluation of an ongoing clinical research trial. I was there to seek answers to particular types of questions specific to retention, adherence, and acceptability of study protocol. However, a bigger tension was palpable and transcended the concerns of the study I was there to verify: the engagement in research as transactional. For the people most impacted by HIV in Peru, namely, people of diverse genders and sexualities, the HIV risk inherent in employment (i.e., sex work), complexities of resource instability, and legacy of HIV research as

the primary source of care is a contextual reality that blurs the concepts of motivation and “free-will” regarding research participation.

A core ethical principle for conducting medical research among human subjects is the notion of volunteerism. This is defined as participation motivated by one’s free will, specifying that the research does not include coercive practices that compel participation based on real or perceived force, authority, or intimidation. But in practice, the social realities surrounding human subject participation, such as economic marginalization and limited access to medical treatments outside clinical trial settings, frequently blur the line between coercion and free will (Abadie, 2010; Biruk, 2012; Crane, 2013; Fisher, 2008; Nguyen, 2010; Petryna, 2009; Rajan, 2006).

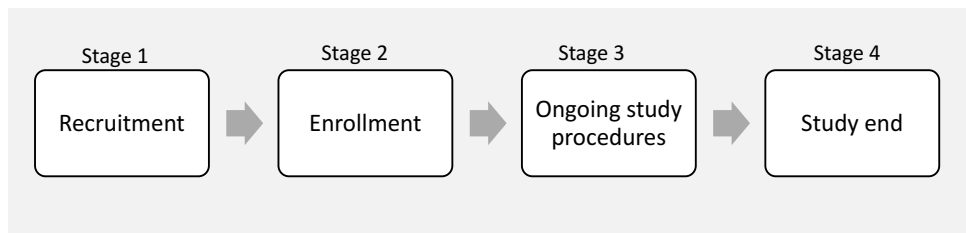
Building on Marxist attention to the political economy of labor and value, social scientists have applied these ideas to the biomedical sciences with the concepts of bio-value, bio-capital, and their circulation within a bioeconomy (Cooper & Waldby, 2014; Gross, 2011; Hardon & Sanabria, 2017; Novas, 2006; Petersen, 2013; Petryna, 2005; Rose, 2007). Cooper and Waldby introduce the term “clinical labor” to bring attention to the often invisible yet complex work needed to convert humans into experimental subjects and traded biological material used to sustain lucrative biomedical and pharmaceutical research (Cooper & Waldby, 2014). Continuing these critical inquiries into the labor involved in clinical trials, this chapter furthers understandings of the governing logics of global HIV science that transform the relationships between people and organizations into transactions at every stage of the research process.

The previous chapter explored how capitalist practices operate within global HIV research focusing on certain identity groups, namely, gay and bisexual men classified as MSM and transgender women become commodified identities, and are turned into an economic venture in the local context and traded in the global marketplace. This chapter extends this

approach by examining the research enterprise, and micro-economies at each stage of the process, that form around people classified as human subjects. By assessing the different forms of labor and transactions embedded in this process – those among participants as well as study recruiters and clinical staff – this chapter complicates the nature of participation, volunteerism, and free will in conducting HIV biomedical prevention research. In what follows, I show that research is comprised of multiple components that build on each other (i.e., a research assembly line) to create a complete research study. Participants move from recruitment to enrollment to ongoing study procedures and, ultimately, to the study’s end. This process should be understood as taking place within an intricate ecosystem comprised of participants, community-based recruiters, and study staff – an ecosystem in which compensation, value, and labor shape all interactions.

Drawing on participant observation during clinical trials with active and former research participants, this chapter explores each research stage independently to highlight unique aspects of the micro-economies at play throughout the larger process. Described in chronological order (as one would hypothetically pass through the components of a study protocol, see Figure 5 below), this chapter shows how HIV science in this context feeds into the larger global health industry. While Peru is considered a science success story of how to conduct HIV biomedical research among people categorized at MSM and transgender, I demonstrate the vast amount of work required to achieve this reputation.

Figure 5: Chronological Visual of Clinical Research Components



Stage 1: Recruitment

Across biomedical research, target enrollment goals and study population sample sizes are based on hypothetical calculations. Sample size calculations estimate the total number of data points (in this case, people) needed to fill an abstract sample with enough statistical power to detect differences in quantitative analyses examining the effect of exposure (intervention) on outcome. However, in grants and protocols, the rationale for a study's sample size is based on statistical requirements, and fails to consider numerous on-the-ground realities, such as, in the case of Peru, the high demand for participants in a context of multiple concurrent studies.

This disconnect between the hypothetical sample size in the study design phase and the challenge of achieving the recruitment quota in research implementation is one of multiple examples of the tensions that emerge while *doing* research. This section argues that the process of recruitment is a complex dance, which requires negotiating participants' subjectivities and varying levels of commitment, and the role of interlocutor frequently falls on peer recruiters who are both on the front lines of the study and part of the community. As a result, recruitment of research participants is one of the most crucial, yet undervalued, jobs among study staff, especially within a context of multiple concurrent studies.

Lima is an illustrative case, showing the work required at the recruitment stage, how work is valued, and the emergence of competition generated among recruiters, participants, and research teams when several studies simultaneously engage in recruitment. This is particularly noticeable for research focused on those classified as most at-risk for HIV – namely, people categorized as MSM and transgender women – compared to studies focused on the general population, as there is a smaller pool of eligible participants. For example, in January 2018, there

were at least five ongoing research studies in Lima actively recruiting people categorized as MSM and transgender women as their target populations²⁷. From on-the-ground observations, leadership teams engaged in infrequent cross-study discussions regarding overlapping recruitment efforts and their potential burden on the people these studies sought to recruit. As described by Pedro, a peer recruiter, “It’s hard to recruit people to my study when the other studies pay them more” (Pedro, interviewed May 2017). Similarly, Lorena, another peer recruiter, “There is a lot of pressure to recruit participants quickly... but the investigators don’t understand that recruitment is difficult especially when so many *travestis* are already participating in research” (Lorena, interviewed October 2017).

An important and unique aspect of the Lima context is that the recruitment process primarily involves people of diverse genders and sexualities in two senses: as recruiters and as participants. Thus, the pressure to find participants manifests in particular ways and has spurred distinct micro-economies in the recruitment process that reflect how labor is valued within it. In this construction, peer recruiters have been situated as a class of laborers separate and hierarchically below salaried study staff (i.e., those who are clinically trained and responsible for implementing the biomedical components of the study protocol). Value is placed on peer recruiters’ knowledge of local context and community structure *and* their gender and sexual identities, which mirror those of the people they seek to enroll into the target research sample. As

²⁷ Per NIH reporter and knowledge of ongoing studies, these include: 1) PrEPTrans (observed as part of this ethnography) 2) Mujeres (observed as part of this ethnography); 3) AMP (Antibody Mediated Prevention/ *Anticuerpos me protegen*) (HVTN 704/HPTN 085) and ongoing recruitment across three different clinics throughout Lima; 4) Combination HIV Prevention, Linking Prevention and Care, for Hispanic Men (R01MH109401); and 5) MSMComb (Observed as part of this study). Notably, study titles are frequently misleading; sometimes the publicly available abstracts denote the study population as MSM or MSM/TW and sometimes they do not. Additionally, studies like Mujeres that are funded by private foundations (in this case, the American Medical Foundation for AIDS Research [AmfAR]) are not obligated to discuss financial information, as are studies funded by taxpayer dollars (i.e., public funds). Please note that the names of 3 studies observed are pseudonyms. Further information can be found in Appendix A.

a result, the recruiter role requires skillful navigation of disparate spaces (i.e., clinical versus community) and constant negotiations between social boundaries (i.e., membership in the LGBTQ community and ownership over recruitment of “hard-to-reach” populations).

Peer recruiters are frequently hired as contract laborers, and in a precarious economic situation, and can be fired and replaced more readily than salaried employees. As a result, they often police the boundaries between the kinds of work they are especially able to do to prove that they are the ones best suited for the job versus another study staff (i.e. those who are cisgender and/or heterosexuality-identified). Luis, a recruiter working across three different studies, explained, “I am gay. This is my community and I know how to get my community to participate in research. It is much different for information about a study to come from me than from someone from outside of our community” (Luis, interviewed March 2017). There are also boundaries established between peer recruiters and participants, as recruiters earn a level of prestige from being on the inside of the research process. As Nikki, a *travesti* who became involved in research through participation and now works as a peer recruiter, stated:

I got involved in [this study] because a friend told me about it. It was my first time participating in a study and I really liked it... I liked being with other *trans* and learning about ways to help my community. I liked that there were services just for us [transwomen]. The more time I spent with the other facilitators and recruiters, the more I wanted to be involved. I think that they [study staff] also saw in me someone that could help. Now I am a recruiter and I can share important information with other trans... You know, unfortunately, many of us don't have enough information and it is the responsibility of us who are empowered to educate. (Nikki, interviewed June 2017)

Many of the peer recruiters interviewed similarly acknowledged that social and cultural capital are associated with success in recruiting and being hired on future biomedical research studies. However, this value exists in stark contrast to the unstable reality of clinical study-based work; namely, the governing structures of global health research that make such jobs temporary,

labor-intensive, and underpaid. Payment structures place value on process versus people. For example, recruiters are paid “per head,” meaning per person they recruit to the study, and they are paid the same amount as the participants. Said differently, if a potential participant is paid 20 soles (approximately \$6 USD), the recruiter will receive the same amount for each person they recruit. In this way, peer recruiters are incentivized economically to bring in as many people as possible.

Institutional review boards (IRBs) governing the ethics of conducting research with “human subjects” oversee the amount of economic incentive provided per study. However, there is no analysis or regulation across active studies. As a result, in a competitive research climate like Lima, financial remunerations are diverse, and consequently influence which studies are considered most desirable among peer recruiters as well as potential participants. Importantly, one study known as AMP (Antibody Mediated Prevention), which in 2018 began recruiting people categorized as MSM and transgender women across four clinical sites in Lima, was providing incentives in US dollars, not in soles, the Peruvian currency. The rationale behind this decision, as described by Dr. Lucca, the Peruvian principal investigator, was, “We give dollars, not soles, because of currency fluctuations. This is what the network²⁸ implemented and this is what we do... Additionally, participants seem to like it more so it helps with recruitment” (Dr. Lucca, interviewed August 2017).

AMP compensates a standard study visit with \$20 USD, and a visit that involves a transfusion (and thus takes more time) with \$50 USD, which is the equivalent of approximately

²⁸ “Network” refers to the funding agency. AMP is currently being conducted across four clinics in Lima and is funded by the National Institute of Allergy and Infectious Diseases (NIAID), part of the U.S. National Institutes of Health (NIH) but run through the HIV Prevention Trials Network (HPTN) and HIV Vaccine Trials Network (HVTN).

65 soles and 163 soles, respectively. To give a sense of scale, in comparison, the minimum living salary in Lima is currently 850 soles per year, which is about 254 soles per month and 8.50 soles per day (“Este mes sube el sueldo mínimo y depositan la CTS,” 2016).²⁹ In this context, AMP’s incentives are substantial in the current landscape when compared to other studies that pay between 25 and 55 soles per study visit. Beyond amount, when learning that financial incentives were paid in USD, potential participants who seemed uninterested or on the fence about participating were convinced. Furthermore, peer recruiters tended to know about AMP and those who worked there were proud that “their study” could pay people more and in USD.

Interestingly, while AMP represents an extreme case in economic compensation, it is still plagued with the common challenges of managing competition between sites and participant fatigue. In Lima, there are four AMP sites that provide the same remuneration, and so recruiters devise creative strategies to recruit people to their sites and away from others. Some enacted performances that emphasized the convenience of their site’s location, staff with a reputation for providing good care, and other benefits, while highlighting negative rumors about other sites. The sites themselves, while they cannot change the monetary compensation provided, do have the autonomy to offer merchandise and snacks to further incentivize going to their site versus another. Notably, these strategies are most commonly used to retain participants in ongoing study procedures versus initial recruitment efforts.

Competitions within this micro-economy are known and, at an expert level, both Peruvian and US-based researchers voiced concerns in personal interviews about how AMP procedures will impact future study recruitment. For example, Dr. Pérez, a Peruvian physician-

²⁹ Previous scholarship highlights the tensions between institutional review boards and human research ethics committees who aim to keep incentives low to discourage economic coercion yet, in reality, set research compensation higher than minimum-wage rates. (Abadie, 2010; Cooper & Waldby, 2014)

researcher, explained “unless we continue to do network studies, I doubt we will have the budget to give incentives in dollars. Now participants want dollars and not soles” (Dr. Pérez, interviewed May 2017). Dr. Dover, another US-based researcher, commented, “It is ludicrous that compensation is in American dollars and that such an amount was approved by local-IRB. It is the very definition of coercion” (Dr. Dover, interviewed January 2018). Concerns regarding the amount and currency of financial remunerations are magnified when, as others have also shown, the profile of who is recruited to participate in clinical trials is influenced heavily by economic marginalization (Cooper & Waldby, 2014; Petryna, 2007). And among people with diverse sexualities and genders, it is infrequent to come across a recruiter or potential participant that has a stable income, or who does not engage in sex work.³⁰

Even so, people are not always convinced by economic incentives to participate in research. As I observed, agreeing to be recruited typically depended on two primary factors: the peer recruiters themselves and logistical issues. During recruitment, potential participants are most commonly situated face-to-face with members of their communities in personal spaces, such as where they live or where they work. Often, recruiters choose spaces in which several people classified as MSM and/or transwomen congregate, since engaging multiple people at once would increase their earnings. Also for this reason, recruitment takes on a showman-like quality, with information about the study and its potential benefits scripted and delivered dramatically.

Peer recruiters also rely on their reputation in the community to leverage the value of their endorsement. For example, “You know I’m well respected, so when I say that this is a good

³⁰ This is not necessarily the case for study staff. Although there are self-identified gay men and transgender women are contract employees working for research studies, they frequently represent a higher socioeconomic stratum compared to people who participate in the study. See Chapter 3 for description of the distinctions between peer recruiters versus study participants.

opportunity, it is,” (Joaquin, Peruvian peer-recruiter, observed August 2017) and “I’ve been part of studies for years and if I could, I would participate in this study” (Jana, Peruvian peer-recruiter, observed August 2017). If the recruiter is particularly well liked, they can at times even position participation in the study as a mix of a personal favor to them and a personal benefit for the potential participant.

Additionally, when peer recruiters earn positive reputations within research leadership circles for being fast, efficient, and hardworking, they are often asked to “help out” if recruitment is going slowly. Acquiring expertise as a peer recruiter is thus a social process, linked both to one’s standing in the community and one’s ability to showcase their skills in recruiting. Research organizations capitalize on this hierarchical structure, and while they still pay on a contract basis, peer recruiters deemed as “fixers” are frequently compensated more compared to other peer recruiters on their teams. A recruiter’s reputation works both ways, however, as competition between recruiters, like competition between sites, also spurs gossip – such as intentionally recruiting fraudulent participants (i.e., people known to be living with HIV for studies that only enroll HIV-uninfected) – that can negatively impact success rates. Relying on one’s social standing could also backfire and be perceived as unwanted pressure, as Franco, a former peer-recruiter, illustrates: “I understand that studies are important, but I don’t have the time right now and I am tired of being pressured by friends to participate” (Franco, interviewed July 2017).

The transactional nature of research recruitment is also illustrated by social events that studies orchestrate with the purpose of attracting potential participants. Known as study launch parties, these frequently occur at night in discotheque-like settings – an alcohol-free environment where scientists, study staff, peer recruiters, and potential participants awkwardly mingle under the flashing of strobe lights. Studies frequently hire drag queens to perform, which has been

openly critiqued by the trans community for demonstrating a lack of understanding of gender as an identity and not a performance. Consequently, peer recruiters' direct efforts are generally the more effective strategy.

The second key factor influencing participation is logistics. Since many potential participants engage in sex work, they typically reserve daylight hours for rest and thus voice hesitations about the length of time that initial recruitment procedures might take. As one transwomen explained to Yazmin, the peer recruiter I was observing, "I would like to join, but I am tired. If I have to be at the center from 11 [a.m.] to 3 [p.m.], when am I going to sleep? I need to prepare to go out on the street by 6:30 or 7:00 p.m."

Similarly, Blanca, explained that the time involved in enrolling in the study was not only going to the clinic and waiting there, but also preparing to go: "I just can't go like this. I need to put on my face and get ready. That takes time and it is hot, so my makeup won't stay. I'll look bad and then will have to redo makeup and outfit once I get home" (Blanca, interviewed July 2018). Many of the same concerns and questions were echoed across different recruitment scenarios as potential participants weighed their logistical options, including, "How long will this take?"; "How much money [will I receive]?"; "Will I get my test results the same day?"; and "Will transportation be provided?"

In addition to peer recruiters' performances and social capital, and the logistics of the enrollment visit, many potential participants consider the health benefits of joining a study when making their decision. Those not convinced by economic compensation sometimes asked if condoms and lubricants would also be provided, as well as what types of exams would be conducted through the study. Condoms, while free at health posts throughout Lima, were

surprisingly sought after in street-based and brothel-based sex work venues, pointing to infrequent engagement in these services.

Lubricants were, also, highly desired but so rarely obtained that I observed a recruiter including hand gestures and a change in tone to emphasize that “*even* lubricants” would be provided. Routine HIV and STI exams are also a draw for people that choose to engage in enrollment procedures. However, despite recruitment scripts that clearly link medical incentives to a clinical trial and/or research study, there is often much confusion about the distinction between research and routine care. As Jacko, one potential male participant I met during a recruitment outing to the sex-worker zone in the center of Lima, tried to clarify for his friend, “This is your AMP [*atencion medica periodica*, periodic medical attention]. Just go for the testing, the wait is less than at the CERITS.”³¹ This quote draws attention to the frequent and inaccurate conflation of healthcare provided through clinical research with routine care provided by the state. Furthermore, it demonstrates that some potential participants perceive the level of care provided by the NGO and/or CBO conducting clinical HIV research as superior due to the technology provided and the speed that results are ready.

Sasha, a transgender woman who enrolled in four studies but chose not to continue, explained that her motivations for enrollment were rooted in health benefits:

Through these studies I get fast attention and reliable tests to know I am clean. It gives me peace of mind to know that I am clean. You know, my life is *movida* [slang for “in motion,” which alludes to her occupation as a sex worker], so it is important for me to know I do not have HIV. (Sasha, interviewed March 2018)

³¹ CERITS refers to *Centro de Referencia de ITS*—municipal clinics providing STI prevention and treatment services for “at-risk populations,” namely, MSM and transgender women. See Chapter 2 for a brief history of the CERITS established under Dr. Jorge Sánchez.

When I probed Sasha further about what she meant by “reliable,” she responded that she perceived the quality of the tests conducted through research institutions to be superior to those in public medical establishments:

They [research studies] use the latest technology. I trust that when they tell me I am negative, it’s the truth. When you go to the CERITS, who knows that type of test they are using. It takes a long time to know your results and then you get it and you can’t trust that it is true. (Sasha, interviewed March 2018)

Others echoed this sentiment, suggesting that engaging in recruitment and enrollment is a common strategy to obtain higher quality medical testing, as well as the added benefits of condoms, lubricants, and other health incentives.

As a whole, the recruitment phase illuminates the initial ways that conducting clinical trials with marginalized subjects like MSM and transgender women becomes a highly transactional process. Peer recruiting involves intensive labor that requires negotiating community membership and economic necessity, while potential participants must consider the financial and healthcare benefits of agreeing to enroll. Such micro-economies entrenched in recruitment belie simplistic understandings of volunteerism and participation in research. However, this is only one aspect in the larger research process through which data and identities are produced and commodified.

Stage 2: Enrollment

The second stage of the research process further reveals that peer recruiters, potential participants, and now study staff engage in complex interactions in order to conduct research. A variety of labor is necessary to manage the challenges of transforming individuals into data during enrollment, and identity politics – meaning an articulation of politics or positionality rooted explicitly in one’s identity and collective experience – play an important role in who does

what type of work and why. During the recruitment stage, peer recruiters' knowledge of and membership in the LGBTQ community is strategically leveraged as a commodifiable trait, even a requirement (see Chapter 3 for further detail on the commodification of gender and sexual identities).

However, the expertise of being part of and working with gender and sexuality diverse communities does not hold the same value in enrollment stage, where within a more biomedicalized space, leadership and power is reserved for those with knowledge of medicine and research procedures (i.e., doctors, nurses, etc.). This is interesting and surprising, considering peer recruiters' experiential understandings of the structural barriers that people of diverse genders and sexualities confront when trying to access care. Moreover, peer recruiters' labor remains very necessary to retaining participants during the enrollment stage, even if this labor remains undervalued and unacknowledged.

When working with people categorized as MSM and transgender women, the discrepancy in how expertise is valued forces us to consider the tensions between inclusion and tokenism. As I observed, while most principle investigators (including American and Peruvian), physician-researchers, and study staff were gay-identified, and a handful of people self-identified as transgender, there were stark differences between them and participants. These differences were rooted in economic resources and social class. For example, as Jana, a study recruiter detailed, "I am trans, but I am not *travesti*. *Travestis* have a tough life... they work on the street, they are harassed by the police at night and by their family by day. *Travestis* can't be recruiters, they aren't reliable" (Jana, interviewed July 2017). Indeed, valuing non-normative sexual and gender identities representative of the people who participated in these studies was only strategically

incorporated into study procedures and not used as a baseline framework for conducting clinical research.

However, omitting people that comprise the target sample can have consequences. As mentioned by Dr. Dover, a US researcher with NIH-funded research in Peru,

We got dinged in our last grant submission for not having enough community engagement. While we structured our aims to include qualitative and quantitative components, in the resubmission we were forced to include a CAB [community advisory board]. (Dr. Dover, interviewed January 2018)

Further, Dr. Arizmendi, a Peruvian expert with experience working on NIH-funded studies with transgender women, dismissed the utility of CABs:

We included a CAB because we had to. But in reality, CABs are extremely difficult. One, it is almost impossible to schedule various community members to show up at the same time. Then, if they do, they don't understand the aims of the research, and discussions become about other fights within the community. (Dr. Arizmendi, interviewed December 2017)

In addition, when discussing the potential significance of CABs with peer recruiters, most had little to no knowledge that this mechanism existed, which further highlights the precarious place of community voices in research design and implementation.

Moving from Stage 1, recruitment, to the Stage 2, enrollment, physical space demarcates important boundaries that reflect the ways that different labor is valued. During recruitment, work is conducted primarily in community spaces by community members (peer recruiters), whereas during enrollment, the research process shifts to biomedical spaces under the direction of study staff.³² While peer recruiters are central during recruitment and hold important leadership positions in community settings, this power is lost upon entering a clinical research space. As independent contractors, peer-recruiters rarely have the privileges of full-time study

³² During my fieldwork, all research targeting people of diverse genders and sexualities was conducted by private NGO or CBO clinics.

staff. Many peer recruiters, primarily transgender women, bring potential participants to the clinic, inform the guard that they are there to deliver them, and then wait in the lobby or outside for payment from the study coordinators. Despite the usefulness of their actions, without which participants might never reach the clinic, they are treated as a nuisance and discriminated against by security guards and receptionists.

Transwomen are considered a challenging demographic to include in studies. As Alexis, a gay-identified Peruvian study coordinator, explains:

Trans women are difficult. They are difficult to recruit, to enroll, and to retain. For studies that recruit both MSM and trans, many more resources are spent on the trans population... Transwomen come to the clinic and won't wait until their visit. Obviously, they don't get their incentives unless they start the process and the recruiter won't be paid either. (Alexis, Interviewed March 2018)

For this reason, peer recruiters' efforts in helping transgender participants during the enrollment process are particularly important, and yet remain undervalued as unskilled and inferior to clinical expertise. For example, when a transgender potential participant goes to enroll for a trial, a security guard will stop them prior to entering the clinical establishment and ask to see their national identity documents (DNI, *documento nacional de identidad*). While this is common administrative protocol, this interaction can be tense. If the participant's photo, legal name, and sex marker (reflecting sex assigned at birth) do not match their physical presentation or social name, they will often experience discomfort or, worse, recurrent systemic discrimination.

If transwomen make it past the security guards and/or receptionists, clinical staff frequently call potential participants by their legal first names instead of using their social or last names, and/or use pronouns that do not reflect a person's current gender identity. In doing so, clinical staff thereby alerts others in the vicinity that the person is transgender. This is the case even though most of the CBOs and NGOs that specialize in conducting HIV research among

sexual and gender-fluid communities should be familiar with gender affirming procedures. If the potential participant is unaccompanied, they will often turn around and leave, choosing not to proceed with research procedures at that time.

Furthermore, many transgender women identified such experiences with mistreatment in healthcare settings, perpetrated by clinical staff and others, as one of the primary deterrents to accessing care. Peer recruiters (some of whom are on the transfeminine spectrum themselves, identifying as trans, transgender women, *travesti*, etc.) address these issues by entering the clinic with transgender participants. They attempt to alleviate tensions with security guards or other front-line staff, support and protect the participant from possible discrimination, and ensure that they commence with enrollment procedures. Indeed, while these interactions are undervalued and important labor for the study, it also ensures their own payment and key role in these studies.

In addition to their efforts to prevent experiences of stigma and discrimination in clinical settings, peer recruiters attend to other participant problems during the enrollment process that study staff rarely acknowledge or address. Among them are the logistical challenges of reaching the clinic, especially for transgender women. Many transwomen indicate that they are more comfortable in a taxi than on a bus, especially during the day considering the frequent snickering, pointing, and verbal harassment they experience on public transportation. However, if a potential participant needs to travel from central Lima to a clinic site in southern Lima, it can cost 10 soles for just one way. If they are only given 20 soles as compensation, they would spend it all on the journey, as well as lose valuable time and sleep. Given these circumstances, several potential participants voiced that they would prefer to not go. As a strategy to solve this problem, recruiters often group several transwomen together in one taxi in order to share the cost and

accompany them to the clinic, simultaneously helping them through initial barriers of entry and securing both their own and participants' payment.

Unlike peer recruiters, whose labor is undervalued during the enrollment stage, research participants are characterized as volunteers who receive compensation for their time, versus wages for providing labor to studies. Thus, their labor goes unrecognized as such throughout the research process. During recruitment, their labor not only involves sitting through recruitment pitches and getting to the research facility, but also often includes the accompanying stressors of gender-identity and sexuality-based discrimination. The enrollment stage, depending on the study design, typically requires much more of participants. In the five ongoing research studies that actively recruited people categorized as MSM and transgender women in January 2018, the procedures during the enrollment visit involved obtaining biometric samples, including blood (and for two studies, anal swabs), and a survey consisting of 150 to 250 questions. These procedures lasted anywhere from two to four hours, not counting the wait time at the clinic.

There is also the added dimension of participants' emotional labor during enrollment, as study staff exercise investigative techniques akin to probing to assess whether the person is eligible to consent and participate in the study. At this stage, it is the staff's responsibility to construct a study sample for clinical trials that matches the eligibility and exclusion criteria set forth by the principal investigators. As Dr. Erikson, a US principle investigator leading HIV biomedical prevention studies in Peru, described, "We are trialists and live and die by inclusion/exclusion criteria. This is a core component of any training we give to study staff" (Dr. Erikson, interviewed May 2018). Such training sessions, especially for counselors, emphasize the importance of probing or fishing to tease out whether potential participants were eligible, such as offering personal anecdotes to encourage participants to reveal intimate truths.

For studies enrolling people classified as MSM, this technique might be intended, for example, to uncover sexual orientation when behavior is not synonymous with identity—unfamiliar territory for some study staff. As Paquita, a heterosexual study coordinator, explained:

I am married to a man and have two kids, so before I started to work here I had never heard of MSMs. It was difficult for me to learn that a man could be having sex with another man and not consider himself gay or bisexual. It also took me a while to learn that a male could say that he was having sex with a woman but mean he was having sex with a transgender woman...It's complicated and people don't want to tell you who they have sex with... so you have to build trust and then ask questions. That can take time. (Paquita, interviewed June 2017)

Juan Carlos, a gay-identified counselor and study staff, detailed:

I have had several *heteros* [heterosexuals] come in and tell me they are a man and only have sex with women. I know that they were recruited for a reason and tell them that this is a safe space and clearly ask them why they are interested in a study for MSM or how they ended up at this study... because I know that while they say only women, a *flete* [slang for male sex worker] or two are likely to have crossed their path. (Juan Carlos, interviewed March 2018)

In seven of the training sessions I attended anecdotes such as these were provided to educate study staff in non-heteronormative sexual practices that they might encounter. However, they also served to train staff to push and probe on intimate details with an underlined understanding of sexual promiscuity and stigmatizing imaginaries of sexual secrecy and deviance. As I observed, typically the use of anecdotes such as these, resulted in chuckles or nods of acknowledgement for the audience being trained.

But notably, trainings did not include a discussion of why people might not be forthcoming in describing their intimate sexual acts, or how a clinical setting might interfere with facilitating these conversations. Instead, the implicit understanding was that lying and manipulating the truth to hide promiscuity, as well as to receive their compensation or other incentives, were commonplace among potential participants. Trainings providing strategies for

dealing with transgender women participants emphasized this point, stressing the importance of catching a potential participant in a lie intended to mislead study staff so that they would be enrolled and collect the incentives. Warnings included anecdotes of transwomen living with HIV who knew their status, some who even took antiretroviral medications, but feigned ignorance about their status in order to be retested and collect the economic compensation from the enrollment visit.

In addition to screening for eligibility, study staff assist potential participants in completing lengthy surveys, and conduct biomedical procedures linked to the baseline collection of biological data (i.e., blood, hair samples, etc.)—procedures that signify that a person has been recruited and enrolled, and is now a participant.³³ Staff trainings acknowledged that the survey is long and burdensome for both participants and staff, but repeatedly conveyed the importance of collecting complete and accurate data. Trainings also provided gold standard suggestions, including reading questions aloud in private, confidential spaces if participants need help, and checking in periodically to ensure that all questions are completed. However, these suggestions remained disconnected from the reality of implementation, which was characterized by overburdened staff and tired participants who were sick of waiting and frustrated by spending two hours or more answering a survey.

During one site observation, two counselors had five participants begin enrollment surveys for two different studies at the same time. Because there were only three available private consult rooms for five people, the counselors had a private discussion to consider which of the participants were most likely to refuse or stop halfway through the survey. Given the expectation of incomplete data, these were then the two people selected to complete their surveys

³³ In the process of becoming a participant, all identifying information is masked—people are assigned a participant ID number (PTID).

out in the hall. It took participants between one hour and forty-five minutes and two hours and fifteen minutes to complete their surveys.

As I observed, the survey was not easy to fill out and each participant summoned the counselors at least twice (one participant five times) to ask questions and all commented that the survey seemed repetitive. Their annoyance was obvious as they voiced frustrations with the length of time, during which they could be doing more important things. Due to conducting multiple studies simultaneously and the resulting competing demands, all five participants were asked to wait longer once they completed the survey to either receive their results or partake in post-counseling study procedures. Notably, only one of the studies had the budget to provide snacks, so while all were asked to wait longer, a division appeared in the waiting room between those participants who were given a small juice box and crackers and those who were not.

Conversations with counselors and study staff across multiple NGOs and CBOs illustrate a similar reality. While all five participants stayed in the scenario described above, study staff identified the wait time in enrollment procedures as a key moment in which people drop out of the study. However, it is significant to note that potential participants typically receive their economic compensation at the end of enrollment procedures, in the exit interview. This timing calls into question whether participants are volunteers, free to leave at any time, or laborers providing a service and being paid a wage. While compensation rates are kept low to avoid economic coercion, as dictated by in-country and global North IRB regulations, the amount is still substantially higher than minimum-wage rates in the Peruvian context.

By analyzing the shift from recruitment to enrollment, this section shows the required labor from peer recruiters, study staff, and the potential participants in the transformation from person to potential study participant during enrollment. Significantly, this involves transactions in

which not everyone benefits equally, and labor that, for some, remains undervalued and/or unacknowledged. In illustrating the challenges associated with the enrollment stage (i.e., long waits, biomedical exams, systemic discrimination, logistical issues, etc.) and various players' strategies to persist in the process, this section reveals a dynamic ecosystem in which participants, peer recruiters, and study staff provide distinct labor in order to implement research.

Stage 3: Ongoing Study Procedures

Researchers, especially those located outside of Peru, recognize with concern the increased chance of participants dropping out of the study once they are enrolled, have begun study procedures, and are then asked to come back. In terms of study design, this third stage is most important to maintain the statistical sample needed to achieve the end goal: assessment of the clinical trial and/or research study's success. Said differently, repeat data measures (i.e., the same questions answered at different times throughout the research process) are necessary for each participant. While the number of repeat study visits depends on the research questions and matching study design, whatever the exposure is (i.e., behavioral intervention, drug, etc.) needs to be administered and observed at several data points to ensure that the clinical trial has enough data to make a claim. Researchers, especially principal investigators, are acutely aware of this need and enact systems to ensure that repeat data collection occurs in the face of challenges that arise.

In this third stage of research, foreign researchers start to have more of a presence in the process, which requires routine video conferencing with study teams based in Peru. These routine check-ins are cumbersome, as US-based leadership often do not speak Spanish, yet the work is being conducted in Lima by Peruvian study staff. While Peruvian principal investigators

or others with leadership positions in the internal employment hierarchy speak English (many of them trained in the US; see Chapter 2 for the importance of US-based training pathways), these reports and check-in calls require quick translations from study coordinators and other research staff not typically conversant in English. Perspectives from those who have the most engagement with participants (counselors, study coordinators, peer recruiters, etc.) are messy and riddled with descriptions of the challenges of achieving study requirements in the allotted time. Yet, English translations, most done by senior-level Peruvian researchers, are strategic, only capturing fixable and/or manageable challenges, and frequently omitting linguistic and cultural dimensions that indicate the study's potential burden on both staff and participants.

Disagreements and conflicts do not occur on these calls; rather, any tensions related to the labor involved in keeping participants in the study play out behind the scenes, away from global North collaborators. Language is part of the reason, but such tensions are also intentionally omitted in order to prove a particular team's ease and competence in doing research. Within this competitive research environment, there are multiple NGOs and CBOs qualified to do this work. As such, there is consistent jockeying as to which is most efficient and easiest to work with. For example, Dr. Lock, a US-based HIV prevention scientist, stated, "I work with Impacta because they have the clinical trial experience to follow protocols and link to the community to get the study done. There are challenges, so as more organizations develop the skills to run these studies I would be happy to consider collaborating with others" (Dr. Lock, interviewed May 2017). Study teams are well aware of the fragile nature of professional relationships, a feeling that is especially strong during site visits from US-side research teams (which normally occur annually or biannually). On these routine visits, they also employ various strategies to portray research as a smooth and reliable process.

In one observed case, the study was having difficulty scheduling and having participants show up for their three- and six-month study visits. This clinical trial involved administering PrEP and so these visits were crucial to assess adherence to the study drug and potential side effects. A physician involved in the study explained that one of the main concerns with PrEP is that it is a medication for people who are HIV-uninfected. If people seroconvert while on PrEP, meaning acquire HIV, it can cause their bodies to resist antiretroviral therapy and make HIV treatment more of a challenge. Moreover, part of the eligibility requirements for this study identified participants who were considered high-risk, that they reported at least one instance of unprotected anal intercourse in the past six months. Thus, routine medical checks were necessary to ensure that participants continued to be HIV uninfected. However, study staff struggled to locate participants, and many that they could connect with and schedule were missing their appointments.

This issue came up during a routine phone call with the study's US investigators. In Spanish, Francis, the study coordinator explained, "People are scheduled and reminded, but they are not coming in," after which a peer leader and another member of the staff, both of whom worked with retention, echoed this concern. The Peruvian conversation erupted into a three-minute discussion about the contextual challenges they faced, including participants' economic instability (stolen phones), research fatigue (they were sick of waiting), and disinterest. However, Dr. Alvarez, the Peruvian principal investigator put a stop to the dialogue, and responded to the US investigators with the following:

They were discussing some of the challenges related to working with key populations. But now that we know we need to focus our efforts we will pay special attention. I am confident that by next week when we check in we will have better results to report.

Defusing tensions this way appeases global North scholars, yet places more stress on in-country study staff to figure out solutions to their problems as quickly as possible.

In practice, strategies to this effect deviate significantly from study protocols. While protocols primarily include passive retention policies, such as repeat calls, if adherence is lower than expected, the best of the peer recruiters are contracted to re-enter the process and tasked with physically locating participants and linking them back to the study. This involves additional fieldwork into community spaces, meaning going to people's homes, places of work, and known social areas to find participants. Peer recruiters' labor in tracking down participants that choose to drop out of the studies is immense—in time, money, and community knowledge.

As Joaquin, a gay peer recruiter described,

People stop going to the clinic for so many reasons. They can be sick of waiting, have moved, or just no longer be interested. Finding them is one thing, but then convincing them to come is another. Many times, I have to remind them that this is for their health and that this [research] was a commitment. (Joaquin, interviewed September 2017)

Even though the notion of participants as volunteers is a core component of training and high-level discussion regarding the nature of research, in practice enrollment is treated as a contract. Ironically, in observation a few recruiters have even referred to the consent form – a document created to protect participants from coercion and ensure that participation in studies is voluntary – as a contract, to insinuate an obligation or commitment that needs to be fulfilled.

Within the clinical space, if the study has the budget, new incentive structures are devised to maintain interest during long wait times once participants are tracked and brought back to continue study procedures. Within a broader political economy of scarce food and water, the most common strategy is the use of snacks, typically crackers and juice or soda. However, for network studies (i.e., iPrEx, AMP, etc.) budgets also include money for clothing and other merchandise. According to Roberto, a self-identified gay study coordinator, water bottles, shirts,

hats, and other items are given to participants “as a token of gratitude and to help ease the challenges of being a participant” (Roberto, interviewed September 2018).

Yet, material incentives created further divisions within the precarious social environment that emerges when multiple participants in different studies wait together in the same room. Juancito, another study coordinator, commented:

It would really help with retention if participants didn't see or learn about how much people in other studies were making or getting. It is hard to have a participant come into a consult room frustrated because they had learned from overhearing in the waiting room that the other participant was getting paid much more or getting paid in American dollars and was given a water bottle. They then want to switch studies and I have to explain to them why they can't. (Juancito, interviewed February 2018)

Speaking to me in an open room, other counselors nodded in agreement as Rocio, a cisgender and self-identified heterosexual research nurse suggested, “It would be easier for all of us if different days were for different studies. It makes our work much harder to have to calm down a participant before even starting all the exams or survey” (Rocio, interviewed February 2018).

Especially in trials that include biomedical interventions, continuing with research can signify an increased possibility of participants experiencing hazards related to the secondary effects of medications. Consider, for example, the AMP study that pays participants in USD referenced earlier in the chapter. The general purpose of AMP, which stands for Antibody Mediated Prevention, is to give people antibodies that fight HIV. The antibody in this case is VRC01, produced in the US and shipped to offshore sites, and is administered via intravenous infusions.

The AMP study design randomizes participants into three groups: those who receive a higher dose of the antibody in their IV; those who receive a lower dose of the antibody in their IV; and those who receive an infusion of sterile salt water without an antibody (i.e., a placebo). While there is always a risk of adverse effects from the infusion, this study, as with most FDA-

tracked clinical trials, could be audited by the FDA and other regulatory agencies (e.g., IRBs) that specifically look for adverse effects in assessing the safety of continuing the study. As a result, layers of protocols and training procedures are established to carefully track any adverse effects, such as rashes, nausea, etc. These events are flagged and reported according to a hierarchical chain, from study staff to site principal investigator to US counterparts.

In clinical trials like AMP, there is an extreme amount of concern about potential adverse effects, among regulatory agencies and funders, due to exposure to biological agents. Yet, the focus on biological agents limits the consideration given to potential harms that could arise from “routine” biomedical procedures and associated social harms.³⁴ For example, in early AMP study visits that do not include transfusions, between ten and twenty-five vials of bloods are reportedly collected. While no adverse effect may arise from this practice, participants described this aspect of biomedical experimentation as “too much” and “burdensome” (described in Spanish as “*pesado*”), and Giorgio, an AMP participant, questioned, “What are they going to do with all that blood?” (Giorgio, interviewed March 2018).

The social harms related to participating in these studies are more complicated to disentangle. A conversation with Ricardo, a self-identified heterosexual and cisgender study counselor, illustrates that there is participant confusion as to what randomization means, and about whether participation in the study “protects” them from HIV. He was concerned about such misunderstandings, stating,

As counselors we try our hardest to explain that participants need to use protection while having sex even when they participate in the study. This isn’t as much of an issue in AMP as it is in the studies that give PrEP... [But] I worry that people do not use condoms because they think they are less likely to get HIV because they are part of a study. (Ricardo, interviewed February 2017)

³⁴ I use the concept social harm is an umbrella term used to describe any other potential harm, apart from that of administering the biological agent, which can impact the person due to participation in the study.

Potential social harms are also entangled with participants' hesitation to disclose their involvement in research to their social network, including friends and family. As Miguel, a self-identified gay and frequent study participant, describes,

Participating in AMP can be frustrating, mostly because of how often you need to come in [to the clinic] and the time it takes to complete visits. However, you are paid and you feel like you are part of something innovative, like, you are helping science... No, I don't mention the study to my friends, I don't want them to think that I am sick or something, coming to the clinic this much. (Miguel, interviewed March 2018)

This quote highlights two key points. The first is the notion of altruism as motivation for participating and continuing in the study. This idea of "helping science" or giving back to your community is rhetoric that is also commonly used during the consent process. Notably, consent documents make it clear that while participating in the present study does not directly prevent HIV, but that results could, at a future time, have this effect. This imagined benefit is co-constructed and leveraged throughout various stages of the research process. Peer recruiters use similar language to convince people to enroll or participants to re-engage in studies after they have dropped out. Study staff also evoke such imaginaries when participants voice frustrations about the repetition of biomedical exams or the need to complete time-consuming surveys.

The second point evident in the quote is the perceived stigma connected with study participation, which was a common theme across various studies. Miguel indicates that association with a study can lead others in the community to believe one is sick, possibly living with HIV. Likewise, Lorena details, "I told my friends that I was participating in this study. One criticized me for being a guinea pig and the others started to laugh. I think she is ignorant, but I won't be telling them anymore" (Lorena, interviewed October 2017). Peer recruiters and participants alike referenced a pervasive mistrust towards research among the transgender community. Notably, any discussion among study staff about mistrust as a social harm – or

possible deterrent – was missing. Research subjects, especially those who already experience disproportionate social stigmas related to sex work, sexual and gender nonconformity, and perceptions of HIV risk, are further burdened by stigmas attributed to being a research participant. However, as clinical trials become complicated regarding experimentation protocols, it is more difficult to track and draw attention to the embedded social hazards of becoming a research subject.

The production of HIV biomedical prevention data also creates new forms of labor related to drug importation (when drugs administered in trials are not available in-country), as well as storing and transporting perishable data. Again, the AMP study provides illustrative examples. The antibody administered, VRC01 (i.e., the study's biomedical exposure), is manufactured in the US and then shipped to global study sites, including Peru. All trial sites are required to follow the same procedures, yet the complicated and shifting requirements for handling the antibodies can create confusion, frustration, and additional challenges for the work of doing research.

For example, at the study's start, directions indicated that the antibody must be stored frozen, and that once produced (defrosted and mixed with a saline compound) it can either be kept refrigerated for up to seven days or stored at room temperature for only twenty-four hours. About six months later, upon FDA inspection, these procedures were modified to indicate that once VRC01 was produced, it needed to be administered within twenty-four hours and only kept at room temperature for a maximum of eight hours. Due to systemic incompatibilities between these regulations and the lived realities of study participants (e.g., occupations, transportation to clinics), scheduling and getting participants to arrive at their specific timeslot was difficult and led to wastage, associated costs, and general frustrations. Then a year later, the FDA again

reassessed these protocols. As of July 2018, the procedures have been relaxed and once VRC01 is produced it can be refrigerated for four days and at room temperature for four hours.

Beyond such directives from the global North, there are also restrictive, complicated, and often shifting local-level policies that have significant ramifications for certain study staff. These tend to be the individuals that are already overworked and have competing demands due to the simultaneous operation of multiple studies. While it is frustrating for site leaders to admit to wastage and other challenges in following the protocol, the burdensome labor of study retention and scheduling (i.e., repeat calling, fieldwork, etc.), as well as managing the technical biomedical aspects of the study, fall to the staff with the least pay and power. Moreover, these staff members, as in the case of technicians, are frequently independent contractors that can be terminated at any time. These stressors can affect interactions with participants, as frustrations and challenges with scheduling sometimes transfer onto staff's characterizations or stereotypes of participants and, more broadly, to people classified as MSM and transgender, as irresponsible and frivolous.

The *business* of testing drugs on human subjects functions across levels in the research process; at the expert level, this enterprise facilitates the creation of for-profit contract research organization (CROs), salaries for scientists, etc. Trickling down, systems of research are created to uphold CROs and, with these, labor markets of study staff based on knowledge of biomedical procedures, and, in this context, knowledge of and membership within the LGBTQ community. People categorized as MSM and transgender women play a crucial role in these clinical trials, as they are involved not only as participants, but also as peer recruiters. Yet, while the very premise of this research is to assess risk and biomedical prevention among people of diverse sexualities and gender identities, these very people labor without labor protection. As peer recruiters, they

work as independent contractors and, as participants, they are volunteers obliged to assume both the economic and corporeal risks of the biomedical global health economy.

As people move through the research supply chain, the study's end and the outcomes that must be delivered loom large, straining everyday relations between participants, their data, study staff, and research procedures. With each stage of the research process, the data's importance is reified, simultaneously transforming people into participants and finally into data that must be standardized, analyzed, and disseminated. Multiple micro-economies emerge throughout these processes, which illustrates the transactional nature of who provides what to the complete study and, ultimately, calls into question the very premise of the participant-volunteer.

Stage 4: Study's End

The temporary nature of these studies is explicit throughout each stage of the research assembly line, and it is understood by all that studies typically last between three and five years. However, the ephemeral nature of research work plays out differently for different actors. For principal investigators, about halfway through the study, discussions of the next grant begin. These discussions are explicit, primarily occurring on routine conference calls and via emails attached to progress reports regarding ongoing study procedures.

While it is understood that global North investigators are chiefly responsible for writing the new grants, as money flows through US investigators to Peruvian sub-contracts, the work of preparing to submit a grant falls on in-country Peruvian investigators, and notably, on study staff and contract employees. To apply for a continuation grant, formative data is needed to corroborate the success of the current grant. While the creation of data is a core aim throughout the research process, from study inception through implementation, as a study nears its end, data

becomes imperative and is symbolically imbued with the weight of imagined futures to sustain the existing structures of current research.

In this final stage, human research subjects are no longer the primary focus, even though study staff must continue to dedicate substantial labor to maintaining participant visits and completing study-end surveys in order to conclude the research. Principal investigators and those higher on the research hierarchy, however, shift their focus to analyzing the quality of the data collected and translating data into deliverables in the form of peer-reviewed publications. This shift in priorities is disconnected from the ongoing challenges of completing the research. Study staff are under extra pressure from superiors to complete data collection faster and cleaner (i.e., complete surveys without missing values), but often with less resources, as budgets become increasingly tight and any extra funding is used to pay for analysts and additional research support to write the manuscripts.

Understandings of how a study will end or what it means for a study to end also differ. For studies funded by the US National Institutes of Health, end dates mean that no additional research procedures related to the study can continue after a certain calendar date. While in some cases, a one-year no-cost extension can be granted, end dates are usually not flexible and require hard stops. Clinical research leadership understand these regulations, as it is part of their training, both formally through higher education and informally by learning how to *do* NIH grants. Yet, among some study staff, especially those with the most contact with study participants, these regulations are perceived as unfair, and sometimes contested.

For example, in PrEPTrans, the end date after a one-year no-cost extension was set for July 31, 2018. On several observed calls and email correspondences, Paquita, study staff voiced her concerns, asking, “Do you mean the participants that should still be getting their medications

can't simply because the study has to end? What if we have PrEP? What if they want it?" Paquita also wrote an email in another instance, "I would like to ask for clarification, what does it mean for the study to end July 31, 2018? I worry that for transwomen recruited in the third cohort, they will not have access to PrEP for the same length of time compared to the other transwomen enrolled in the previous two cohorts. I was hoping you could provide further clarity."

For other study staff, especially those who are contract laborers (i.e., peer recruiters), a study's end is a precarious time of proving logistical know-how and value that can be carried forth to work on another study. They create new professional identities to reflect not only their knowledge of study procedures with MSM and transwomen participants, but also their expertise in navigating studies that administer PrEP. This expertise takes the form of knowledge and rhetoric related to PrEP as an HIV prevention modality, and an understanding of the difficulties and strategies for maintaining participant adherence (i.e., ensuring that they keep taking the study drug). As Luz, a peer recruiter, shared with me,

It is a shame that these studies end, as they are important for our community. But I hope that there will be another one soon, as transwomen, especially those of us who engage in sex work, need access to prevention like this pill, PrEP. Before this study I never knew this technology existed. Now, I want to tell my friends about it and encourage them to take it. (Luz, interviewed July 2018)

Significantly, the end of a study means the end of the study drug (if given), routine medical care, and incentives for participants that have been part of the process for years. Although counselors and nurses explain to people who are enrolling that the study will eventually end, all the participants I spoke with voiced disappointment and frustration about the concluding services. They responded to the last community workshop for PrEPTrans, for example, with mixed emotions, from anger to frustration and sadness. Yet, while biomedical research is unstable and

temporary, it has also been a constant within this context for the past twenty years (Glass et al., 2018).

The ups and down, starts and stops, of numerous studies also create an understanding that another study will be available. When one participant, Elvira, questioned, “Will we no longer be able to meet to have these discussions? Will we be able to continue to receive PrEP?” Yasmin, the peer facilitator explained, as trained, that group discussions could continue, but would no longer be organized by the study and that the space would no longer be available once the study ended. However, Yasmin told participants that PrEP is available in Lima and they could either buy it or enroll in another study to get free PrEP. In response, Blanca, another participant critiqued,

How am I going to pay for PrEP? How are any of us going to pay for PrEP? [...] I don't want to enroll in another study to get the medicine. I like the doctor I see here, and wish I could continue. These studies always tell us [transwomen] that we are risky and need to protect ourselves from HIV. That's why we are here, that's what we are doing. But then the studies end, how are we supposed to really protect ourselves?

Participation as Transaction

While high-level actors in clinical research (i.e., principal investigators, funders) view the process as both voluntary and seamless, this is far from true. It takes considerable effort and creative strategizing to deliver the final product, and not everyone involved benefits equally. As this chapter has shown, HIV science requires an assembly line of different components that collectively create an intricate multi-stage process. By looking closely at this process – from recruitment, to enrollment, to ongoing study procedures and finally study's end – we see the extreme amount of work necessary at each stage to transform people into participants and participants into biological data to be delivered to the final customer; typically, global North researchers and/or funders.

On the ground, this research assembly line should be understood as taking place within an intricate ecosystem comprised of participants, community-based recruiters, and study staff—an ecosystem in which compensation, value, and labor shape all interactions. The nature of this work is transactional, in which people exchange money, favors, condoms, necessary healthcare, etc. for participation. Furthermore, clinical research practices, like offering routine testing, condoms, and, importantly, economic incentives structure how healthcare is constructed and obtained by people of diverse gender and sexualities. However, it is not only the human subjects that take part in research in this way. Rather, all actors involved in the research process, including peer recruiters, counselors, nurses, doctors, principal investigators, etc., engage in transactional social interactions to recruit, enroll, maintain, and complete research protocols. The result is the production of various micro-economies circulating throughout the research process.

This analysis demonstrates the significant amount of labor necessary to conduct research, particularly among those at the lower levels of the institutional scientific hierarchy—peer recruiters and participants. It also complicates common characterizations of trial participants as volunteers acting upon free will. This formulation ensures that *their* labor is rarely understood as such. Many participants do join studies with an altruistic desire to help science put an end to the HIV epidemic, but almost none of them participate exclusively for this reason. Rather, their primary motivations lie in economic interests and the need for quality healthcare, both of which are necessary for their survival.

Moreover, this process regenerates and relies on inequalities. As Crane argues (2013), this “uncomfortable mix of preventable suffering and scientific productivity has been the making of a ‘global health science’ that paradoxically embodies and even benefits from the very inequalities it aspires to redress” (Crane, 2013, p. 7). The Peruvian case study builds on our

understanding of “valuable inequalities” (Crane 2013) by examining the ways in which the identities of people of diverse genders and sexualities are commodified. HIV science in Peru is built on research studying people categorized as MSM and transgender women. Social marginalization and economic instability are the structural inequalities that increase their vulnerability to HIV, yet, these same factors facilitate their recruitment into studies in which they are undervalued, underpaid, overworked, and only provided with temporary healthcare. Ironically, such labor mirrors the issues that contribute to their vulnerability to HIV acquisition. This is the fundamental paradox of HIV science.

Chapter 5

Conclusion

As I actively reflect on my own position and role within the HIV biomedical prevention political economy, I am reminded of Emma, the American PhD student who described herself to me as a “trans researcher.” I used this interaction to demonstrate that claiming to be a “trans” researcher is no longer about personal identity, but about leveraging scientific expertise *about* an identity for personal and professional gain, often at the expense of marginalized communities that include, in this case, those classified as trans. I do not self-identify as a “trans researcher” or an “MSM researcher,” but rather as a social scientist who critically studies global health. Yet, unlike the majority of critical global health scholars who are firmly rooted in the social sciences, I see myself occupying an in-between space as an ethnographic epidemiologist. I not only seek to contribute the critical insights derived from this study to global health knowledge, but also to apply them to how HIV science is done. Even so, like Emma, I am part of the political economy surrounding gendered and sexualized bodies in the contemporary HIV research industry. Consider, for example, my active role in several HIV biomedical prevention research studies funded by the US but conducted in Peru, epidemiologic publications that detail the risk of HIV among people classified as MSM and transgender women, and even this very dissertation.

However, I see two important differences between my work in this dissertation and the political research economy I document. First, this work represents an active acknowledgement and reflection upon the power and politics that shape global and personal agendas related to HIV prevention science. Second is my belief that we, global health researchers, can do better; that it is our responsibility to not only call attention to these issues, but also to propose solutions that

change oppressive systems embedded within global public health practices. Reflexivity is at the core of these distinctions – recognizing that my background, perspective, and position shape the research I conduct and the questions I ask.³⁵ I have been working with gender fluid communities in Peru for over a decade and in multiple roles, as a friend, colleague, activist, and researcher. The stories I have shared throughout this work are not my own, and I take seriously the privilege and responsibility of presenting them as an ally.

Simon Rushton argues that rather than attempting “to take cover behind some bogus claim to ‘objectivity’ or ‘neutrality,’” we, social scientists who study the politics of global health, should be “reflexive about our own positionality vis-à-vis the issues we study—including the solidity of our own claims to expertise and moral authority” (Rushton, 2015, p. 312). Following Rushton, this dissertation is grounded in a thoughtful interrogation of my own motivations, and I acknowledge that my critiques of global North HIV researchers do not exclude or exempt me. Continual reflection of my position inside this research enterprise has underlined the trajectory of this work. It is a catch-22. Indeed, it is my involvement in the study design, data collection and analysis, and training as a global health scholar that has allowed me to have access to and understand the *doing* of global HIV prevention research. But my positionality has also directly shaped my analyses, arguments, recommendations, and criticisms.

This dissertation has drawn attention to the entanglement between the increased visibility of gender and sexual diversity in HIV biomedical prevention science and the market value of people categorized as MSM and transgender women in such research. As I have argued, the HIV

³⁵ The issue of reflexivity and, more generally, paying critical attention to the perspective and position of the researcher has a long history in the sociology and anthropology of knowledge production – one with which we continue to struggle. For readers interested in this intellectual lineage, some suggested citations (Foley, 2002; Fook, 1999; see Gruenberg, 1978; Latour, 1988; Latour & Woolgar, 2013; Woolgar, 1988)

prevention paradigm shaping the 4th decade of the epidemic has made the health and wellbeing of queer bodies the newest object of scientific knowledge and regulation. Notably, the development of drug technologies (i.e., PrEP) to prevent HIV has fueled a marketplace targeting not just groups considered to be at-risk for HIV, but those believed to be *most* at-risk. In this context, the spotlight shined on MSM and transgender women has raises uneasy questions about the ethics of making people of diverse genders and sexualities the next biological target in the fight against HIV and AIDS.

In part, this is what Lisa Forman describes as “the ‘unconscious’ and ‘unacknowledged’ nature of the norms, politics and power that drive global health [that] is a direct byproduct of the processes through which power operates, and a primary mechanism by which power sustains and reinforces itself” (Forman, 2016, p. 197). Through examining the contemporary political economy of HIV biomedical prevention research targeting certain populations deemed most at-risk, I have chronicled and made visible examples of such “unacknowledged” exploitation and unequal gains embedded within this system. These existing power imbalances make Peru a salient case study to illustrate the ways in which the global South is increasingly utilized as a living laboratory to advance therapeutic HIV prevention innovation and testing, despite associated harms.

In spite of this argument, I am grateful to have worked with and learned from the leading biomedical scientists in this arena, and deeply admire their commitment to HIV science. The majority of the biomedical scientists who trained me have also substantially contributed to this dissertation through interviews and extensively reviewing much of the text. Nonetheless, I have not shied away from detailing the inherent tensions between the benevolent intentions of global HIV prevention science, and the reality of how research is done and what clinical trials leave in

their wake. Doing critical global health scholarship isn't about producing an exposé or pointing fingers. It is about continuing to work in partnership with those who have allowed me to work alongside them – but now in a partnership with added dimensions and an expanded mission.

In a way, it would be much easier to present this work as an outsider, rather than have to acknowledge and reckon with my own role in the often unintended yet very real harms caused by HIV biomedical prevention research. However, this is both a challenge and a strength of this analysis. I have contributed to inequitable practices within global health research. I want to use my personal involvement in this enterprise to propose practical and feasible solutions to change the oppressive systems embedded within it.

To that end, in this final chapter, I will outline several actionable changes that can improve HIV biomedical prevention research practices targeting people of diverse genders and sexualities. My suggestions expand upon four underlying themes of this dissertation: (1) making labor visible in biomedical research, (2) problematics of outsourcing HIV prevention and care, (3) reckoning with the logics of “most at-risk” categories, and (4) (PrEP)aring for future HIV prevention research. These suggestions are only a start, offering micro-steps forward as well as larger structural-level changes that will require collective action and political will. As such, I encourage others working at the intersection of critical global health and HIV science to actively grapple with their own roles in the contemporary HIV prevention research enterprise, and to help make these tensions visible and mitigate their potential harms.

Making Labor Visible in Biomedical Research

To begin to consider actionable improvements to HIV biomedical research, it is critical to draw attention to the multiple forms of power that underlie the politics of global health, which impact all involved in this enterprise. Following Jeremy Shiffman, who calls for the “critical need to investigate how epistemic and normative power get exercised in the global health field” (Shiffman, 2014, p. 299), this dissertation emphasizes the normalization of health research as a marketplace. This marketplace functions through a research assembly line – comprised of recruitment, enrollment, ongoing study procedures, and finally study’s end – that requires an extreme amount of work to transform people into participants and participants into biological data to be delivered to the final customer; typically, global North researchers and/or funders. Thus, tenets of capitalism are inextricably intermeshed with global health science and practice—a reality that can no longer go unacknowledged in the Peruvian context. As such, we must recognize participation in research studies as labor, an uncomfortable truth that directly contradicts ethical principles of human subject experimentation.

Making participant labor visible brings to the fore the contradictions within the dominant understanding of research participants as volunteers. Acknowledging this tension is the first step in seeking solutions, such as participants’ ability to claim fair wages and international regulatory agencies’ responsibility to monitor compensation and more accurately address potential coercion. This dissertation is in conversation with a growing body of critical analyses that problematize the notion of volunteerism as a core ethical principle for conducting medical research among human subjects (Abadie, 2010; Cooper & Waldby, 2014; Crane, 2013; French & Miller, 2012; Nguyen, 2010; see Petryna, 2009; Rajan, 2006; Yates-Doerr, 2017).

Throughout this dissertation, I have provided examples that trouble the assumption that

participation is driven by free will by making visible the coercive practices embedded within global health research. For instance, I frequently observed peer recruiters leveraging economic incentives as a strategy to recruit participants. I want to be clear that while recruiters should be made aware that this strategy can be coercive and urged to avoid it, this is not the solution I propose. Simply providing further education to peer promoters would not work, as their actions are in response to the pressures and politics of the HIV industry more broadly. Significantly, such strategies are almost built into the recruitment structure, since peer recruiters are primarily contract employees “paid per-head,” meaning that the more people they recruit, the more money they make.

This practice of paying peer recruiters per research participant is not unique to Peru. Given the underlying pressure to collect more and more data that illustrate patterns of disease, this is a pervasive practice in global HIV science. As another example, detailed in Chapter 3, one study I observed provided high economic incentives in US dollars, not in *soles*, the Peruvian currency. For this particular study, the average visit compensated participants more than eight times the minimum daily salary in Lima, and the fact that payments were in USD was perceived by potential participants, study staff, and experts as more desirable. Furthermore, due to competition among simultaneous prevention studies, such incentives are frequently leveraged to encourage enrollment in one study over another.

Practices such as these need to end, as they facilitate coercion and underscore the transactional nature of research participation. Stopping “pay per-head” strategies and other explicitly exploitative labor practices are within the power of research teams’ leadership. However, given the nature of these transnational research endeavors, frequently the onus of addressing this issue is placed on the in-country principal investigators, those with expert

knowledge of the context, while absolving foreign researchers of any fault. In contrast, I suggest that this should be the responsibility of the entire leadership team, both global North and global South researchers alike. In my experience, when presented with evidence of existing harm and unethical practices, leading investigators from both the global North and Peru move quite quickly to address it and find solutions. But these are defensive responses. Understanding that these practices are pervasive and embedded in the ways in which HIV science is conducted needs to be the baseline. That understanding should prompt proactive discussions *prior* to the start of research in order to mitigate processes (i.e., recruitment) known to replicate inequities.

Additionally, given the large sums of global North HIV science funding to conduct offshore clinical research, greater efforts are needed to ensure transparency across study sites and standardize issues like economic incentives (i.e., how much money and in what currency). This responsibility falls to host country (i.e., Peru) *and* sponsor country (i.e., US) from which HIV biomedical prevention funds originate. One possible suggestion is to make research protocols that include information on recruitment and retention strategies publically available. In doing so, in-country ethical review boards would collaborate with funders and study leadership to ensure transparency and accountability in economic incentives provided to research participants and actively observe differences across studies. This, in part, could help mitigate some of the competitions between research studies.

There must also be explicit recognition of the social realities surrounding human subject participation, such as economic marginalization and limited access to medical treatment outside clinical trials. These factors frequently blur the line between coercion and free will. It is against this backdrop that transnational discussions need to reflect upon why HIV science research is being conducted in resource-limited settings outside of the global North (though that is where the

funding originates) and among socially, economically, and politically disenfranchised communities, such as people of diverse genders and sexualities. Such discussions should address, for example, if HIV therapeutic prevention technologies should be tested in developing countries that have not yet approved the drug. Does the global North have a responsibility to leverage political will to advocate for in-country policies to adopt HIV prevention strategies when clinical trials conclude? In highlighting these issues, I am not suggesting that the system of offshored HIV prevention research be dismantled. Rather, I believe that calling attention to the complex practices of *doing* global health research – practices that introduce new and reinforce pre-existing inequalities in the global South – is a first step in resolving them.

Problematics of Outsourcing HIV Prevention and Care

The current architecture of the Peruvian HIV research field is geared towards supporting the funders' agendas, which in this case study all originate from the global North, primarily the United States. Peru is not the first nor will it be the last offshore clinical research site to advance global health agendas. However, clear lessons emerge from the history of this research arena and analyses that examine the benefits and failures of contemporary HIV biomedical prevention studies. As I have argued, the current structure of and processes within the Peruvian HIV prevention science arena were not inevitable, but rather imported and adapted through a historical entanglement between United States and Peru, which I have termed the *visión gringa*. US financial and social investments in the Peruvian research infrastructure were considerable, and as a result helped Peru flourish as a research site targeting people classified as most at-risk in the global biomedical economy.

Yet the contemporary recognition of “success” in research obscures the need for routine HIV prevention and care for people classified as MSM and transgender women. Peruvians in these marginalized groups are generally afforded only temporary access to front-line strategies to prevent HIV (i.e. during their participation in a study). The lack of sufficient access to basic HIV prevention, including condoms, is a serious problem. This is particularly true among people categorized as MSM and transgender women, who frequently engage in transactional sex practices and often avoid routine HIV testing due to discrimination within medical settings (Perez-Brumer et al., 2016b; 2017; Reisner et al., 2017). In high-income countries, condoms and lubricants are available free of charge in public health clinics and even in certain nightclubs. But, as documented in this dissertation, access to what the global community considers to be “standard of care” HIV prevention tools is often unavailable in Peru. Moreover, free condoms and lubricants are offered through research participation and often leveraged as an extra incentive to participate.

Additionally, the heightened global focus and flows of international funding specifically targeting people of diverse genders and sexualities works to conceal the lack of state-sponsored services to provide HIV prevention care. For example, as Karla explained:

Where is the evidence of the harm caused by these studies? Yes, yes, I know, I get free medication, but for how long and what do I have to do for it? I wish I didn't have to participate. I wish my sisters didn't have to participate. I wish this kind of access and care [provided through HIV biomedical research] was available without being guinea pigs, but that is not our reality. (Karla, interviewed July 2018)

Karla's perspective reveals that the reality on the ground is the existence of a sustained pool of people in need of HIV care who support the HIV biomedical research economy. It would be a gross oversimplification to say that all HIV prevention studies are bad or only cause harm. Rather, as Karla described, the problem is that HIV care is *primarily* provided through these

studies, and only while they are being conducted. Global North-funded research supplies necessary resources, and in many cases the only available HIV prevention and care services. Yet by design, these studies are temporary and exist apart from and independent of the public health system in Peru.

Compounding the problem, the Peruvian public health system is overburdened, and has no incentive to maintain HIV prevention strategies that are temporarily implemented by US-led research efforts. In part, this is due to the cost of therapeutic HIV prevention strategies. But additionally, as Dr. Ruiz, a former Peruvian public official dedicated to HIV policy, noted:

MSM and *travestis* are only part of the Peruvian population with urgent health needs. If you want me to be honest, right now we are in a crisis due to Venezuelan migration... And after this there will be another crisis. I am glad that at least some care is being provided to these populations by research studies. (Dr. Ruiz, interviewed March 2018)

Moreover, US scientists who conduct research in Peru ignore their role in the larger context, claiming that sustainable HIV prevention practices are not their responsibility, but that of other experts, such as policymakers, that can tackle the “bureaucratic government” and “chaotic public systems.”

To address this issue, the millions of dollars that annually fund offshore HIV science could, in a sense, be taxed by the host country. Similar to the way that NIH funding awards include direct costs (expenditures budgeted for scientific research and listed in the public domain) and indirect costs (expenditures related to facilities and administration),³⁶ NIH funding could build in costs intended to link research to existing health systems. For example, a percentage of these funds could be put towards purchasing condoms that would be locally available for free. This change would take structural-level action and political will, but as I have

³⁶ As detailed in Chapter 3, NIH does not determine indirect costs; rather, each US academic institution establishes their own fee (i.e., 62% at Columbia University). Yet NIH does limit the number of indirect fees that a foreign institution can charge to 8%.

highlighted in this ethnography, we (those who conduct global health research) need to take active steps to ameliorate harms caused by global health efforts that parallel, yet are never integrate into, existing health systems.

A conversation with Christian, a Peruvian attorney and activist who has spent decades promoting generic medications for HIV treatment, illustrates other micro-level changes that could address this cycle. According to him,

Everyone knows that public systems in the global South are broken and under-funded. That is why science can experiment with our populations... Let's not make the problem worse by testing drugs that are exorbitantly expensive. Let's require that HIV research to only use drugs that are, or could be, available in a developing country context. (Christian, interviewed February 2019)

Christian further emphasized, "Have we learned nothing from the past 30 years of the epidemic? The ways activists demanded equitable and accessible HIV treatment [in the late 1990s and early 2000s], we now need to demand fair access to PrEP and its future derivatives" (Christian, interviewed February 2019).

Christian's call to action is currently a battleground in the United States. Indeed, on May 16, 2019, the United States Committee on Oversight and Reform held a hearing titled, "HIV Prevention Drug: Billions in Corporate Profits after Millions in Taxpayer Investments." Gilead, the pharmaceutical company that produces Truvada, the only FDA-approved form of PrEP, was front and center. Nonetheless, the hearing and subsequent media coverage paid scant attention to the global ramifications of PrEP pricing and testing. This is striking, since Dr. Robert Grant, the principal investigator of iPrEx and iPrEx OLE, highlighted this gross imbalance on the global landscape in his testimony. Describing the procedures of drug importation surrounding iPrEx, he explained:

Gilead insisted on valuing drug shipments based on the commercial price in the United States, rather than the cost of manufacturing, which was at least 300 times less. The

countries hosting the research would tax the importation according to the commercial price listed on the manifest. Administrative solutions to Gilead's excessive valuation of the donated product delayed the research. In hindsight, I wish that we had purchased generic medications for science, which eventually became a common practice outside the US. (Dr. Robert Grant, testimony for the United States Committee on Oversight and Reform on May 16, 2019)

Two days after the hearing, I had a follow-up call with Christian to discuss the US Committee meeting and Grant's testimony, specifically. He reflected, "What's the saying you have in English? Hindsight is 20/20? I don't buy it. If there was really remorse, why is Truvada still only being used?" (Christian, interviewed May 2019). To be fair, there are other actors beyond Dr. Grant who could advocate for generic medications and more equitable practices regarding drug importation. More important is the reality that, as Christian argued, this type of forum "that brings Pharma to task could only happen in the global North." Referring to global health scientists, he continued, "We [Peruvians] need to save ourselves from the saviors."

The point is that although there are discussions about the harms of HIV prevention drug pricing and Big Pharma's unbounded power in the United States, these inequities are magnified when we look at where these drugs are tested and among whom. The global South and HIV prevention research are central to the approval and implementation of PrEP (and its generic derivatives in the future), but the exploitation and inequities at the center of offshored HIV biomedical prevention research are not part of the current discourse. Research is, it seems, untouchable. The complexity of outsourced research often masks the harms caused by the very process. While this research provides a source of expensive and front-line HIV prevention and care technology in resource-limited contexts, it also depends upon the availability of cheap human capital and labor. Moreover, among those conducting the science, these tensions are rarely considered. If they were then steps could be taken to ensure the sustainable

implementation of therapeutic technology post study end in the locations where the research is carried out.

Reckoning with the Logics of “Most At-Risk” Categories

This project illuminates a key paradox within HIV prevention science’s contemporary focus on gender and sexual diversity: this focus gives the impression that the field is committed to progressive health politics, while obscuring and absolving ongoing forms of exploitation and unequal gains embedded within it. Frequently in my discussions about the potential unintended harms involved in doing HIV prevention science, clinicians, scientists, and study staff offered declarations of their own sexual orientations and, less often, gender identities. Most of these higher-level actors described their own path to HIV prevention science as stemming from a personal connection to the LGBTQ community. And although they voiced concerns about the way clinical research is done – for example, MSM and transgender research participants’ socioeconomic profiles and questions of coercion – they used that personal connection to minimize them. By positioning themselves and their research subjects within the same shared community, their competing political interests and starkly different socioeconomic circumstances seemed to melt away. Thus, people of diverse genders and sexualities were homogenized in these conversations.

I do not contest that these narratives are heartfelt. In fact, I truly believe that these actors involved in HIV prevention science primarily do their work with the intent of helping groups to which they feel deeply connected. However, tapping into identity politics in this way promotes an image of HIV prevention research that serves the LGBTQ community as a whole, while it actually involves exploiting those in the population who are, from a socioeconomic perspective,

most at-risk. This disconnect between the “populations” that HIV biomedical scientists study and their imprecise ideas about who constitutes LGBTQ communities and identities at-risk for HIV is very telling. There is an assumption that MSM and transgender women reflect the LGBTQ community as a whole, but, as this dissertation demonstrates, this is not accurate. For example, these self-identified gay Peruvian principal investigators would not be recruited as MSM, as they do not fit the risk profile. Yet, there is no reflexivity in practice about this distinction.

I recommend that more attention be paid to the structural inequalities that increase vulnerability to HIV, like social marginalization and economic instability. These are key characteristics that separate educated, professional gay-identified Peruvian investigators from MSM, *and* put people of diverse genders and sexualities at risk for HIV. Ironically, these inequalities are core attributes in defining MSM and transgender women as risky, yet they become largely invisible through the use of these biomedical categories. Moreover, HIV science in Peru depends on these same factors to facilitate recruitment into studies in which people classified as MSM and transgender are undervalued, underpaid, overworked, and only provided with temporary healthcare.

Irrespective of the sexual orientations and/or gender identities of experts in this field, we also must evaluate the use and re-use of the biomedical categories “MSM” and “transgender” themselves. I follow a long line of scholars who have problematized the usage of “MSM” to detail patterns of HIV risk according to sexual practices and its impact on the lived experiences of people and communities understood to be at-risk for HIV (Aggleton & Parker, 2015; Boellstroff, 2011; Lorway & Khan, 2014; Thomann, 2016; for example Young & Meyer, 2005). More recently, similar arguments have emerged with the rebranding of “transgender” as a biomedical term and its conflation with MSM (Hanssmann, 2010; Perez-Brumer, Oldenburg,

Reisner, Clark, & Parker, 2016a; Thompson & King, 2015). Through observing biomedical prevention studies and analyzing their subsequent data, I have witnessed substantial ambiguity around what these categories actually mean and who is recruited within them. For example, as mentioned in Chapter 2, Pedro, a Peruvian research coordinator and former peer-recruiter, explained:

Obviously when the researcher tells me that he wants to recruit MSM he means gays, *mosteceros*, *fletes*, bisexuals, and until recently also *travesti*. I recruit who I can and say I recruited MSM... What matters for the researcher is that they [MSM] attend the clinic [for enrollment in study procedures]. (Pedro, interviewed August 2017)

As Pedro and other recruiters illustrate, recruiting “MSM,” is an active process that requires cultural reinterpretation to achieve the objective of creating a research population. That the leaders of this research proclaim to share similar sexual identities is somewhat ironic. While people involved in fieldwork on the ground recognize the heterogeneity within the category, this reality is erased as diverse social identities are melded into one homogenous study population.

This disconnect is important. If there is ambiguity and discrepancies with regard to who is classified as MSM and/or transgender, what do the research results mean? These tensions call for a collective reckoning to question why we still use these categories and if there are better options. To do this we must recognize that the HIV prevention paradigm that has emerged in the 4th decade of the epidemic has made the health and wellbeing of certain queer bodies the newest object of scientific knowledge and regulation. The reality is that only certain Peruvians of diverse genders and sexualities (people classified as MSM and transgender women in the research process) are afforded limited access to front-line strategies to prevent HIV. And among these people, access is further limited to human subjects in experimental and temporary biomedical studies (i.e., during the period of the study). While these studies importantly advance

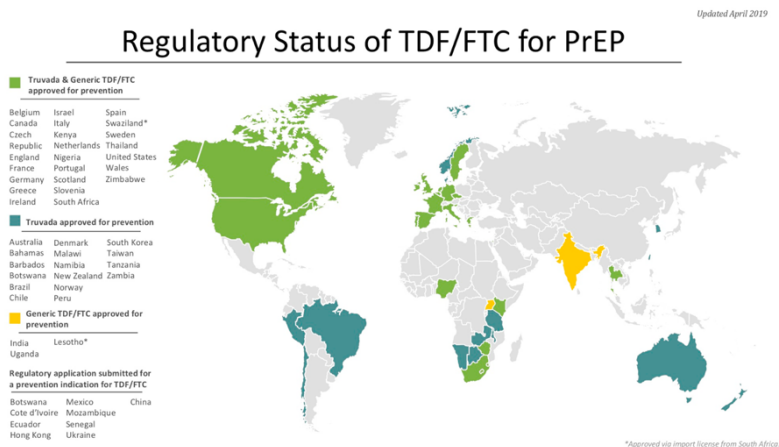
novel biomedical HIV prevention efforts, the translation of this research into policy and drug access is largely limited to the global North.

At this stage, I am not willing to suggest eliminating these categories from research practices. Rather, I am advocating for the use of these categories critically. For example, the Peruvian epidemic, as with other epidemiological descriptions of concentrated epidemics that disproportionately affect people of diverse genders and sexualities, is not depicted as being about endemic poverty, yet that is a primary factor. If we paid sustained attention to the complex realities that make people within these categories vulnerable to HIV, how would that change the way that HIV scientific knowledge is produced?

(PrEP)aring for the Future

At the center of this study is pre-exposure prophylaxis (PrEP), the leading front-line strategy to therapeutically prevent HIV. By tracing early and continued PrEP research, starting with iPrEx, this study documents the difficult ethical balance within human subjects' experimentation, innovation, and access to therapeutic medicines post-study end. My findings are particularly relevant, as we are only at the beginning of therapeutic interventions to prevent HIV acquisition. Indeed, looking more broadly at where PrEP is and is not approved globally (See Figure 6 below for visual map) suggests that we are in the beginning of PrEP scale-up.

Figure 6: Global Agency for HIV Prevention (AVAC) infographic of PrEP regulatory status



A core tension that needs to be addressed in preparation for future PrEP scale-up research is the underlying question of who benefits from offshored research. Indeed, in 2010, when I first moved to Lima, Peru had been recognized as a global “hot-spot” of HIV biomedical prevention trials (J. Cohen, 2006). My timing coincided with the conclusion of the watershed iPrEx trial demonstrating the efficacy of PrEP for certain populations considered most at-risk for HIV, people categorized as MSM and transgender women. By 2012, the World Health Organization named PrEP as the only endorsed antiretroviral medication to prevent HIV among populations most at-risk as a guideline, and by 2014 as an official recommendation (World Health Organization (WHO), 2015). However, even though Peruvians represented over half of the global sample, PrEP was not approved in Peru until 2016. Today, only name brand PrEP (Truvada, manufactured by Gilead Sciences) is approved for use, but it has not been incorporated into the Peruvian public health system. Indeed, throughout my fieldwork I was unable to find a pharmacy outside of those linked to global North-funded HIV prevention research that stocked PrEP.

In 2018, towards the end of my fieldwork, Peru again became a leading research site for the testing of injectable PrEP and again targeted certain populations deemed most at-risk, people classified as MSM and transgender women. Despite the explosion of biomedical research among people categorized as MSM and transgender women, this research has done little to slow the prevalence of HIV. Nonetheless, Peru continues to be globally recognized as a leader in HIV prevention biomedical research. For example, on May 30, 2019, the key contract research organizations in Lima won an award for “data management excellence” from the HIV prevention trials network (HPTN) and HIV Vaccine Trials Network (HVTN) (see Figure 7).

Figure 7: Image of HPTN/HVTN awards in recognition of data management excellence given to Peruvian research sites



In (PrEP)aring for the future, we as global health researchers need to critically examine what incentive structures such as “data management excellence” look like in practice. Accolades like this only reward the end stage of research. In doing so, they conceal and undervalue the very complicated and labor-intensive processes involved in following research protocols. These kinds of awards also fail to convey the daily impact that ongoing and competitive research procedures have on Peruvian investigators, study staff, the lives of research participants, and on the science itself. Instead, it would be beneficial for HPTN/HVTN and other global North funders (e.g., NIH) to be informed about the tensions surrounding categorizing gender and sexually diverse populations as “MSM” and “transgender,” and about the creative, on-the-ground strategies, implemented to mitigate disinterest in studies.

For example, HIV biomedical prevention protocols designed in the US vastly change shape as they are interpreted, adopted, and implemented in the Peruvian context. The social practices and tensions involved in *doing* HIV prevention research cannot be separated from the resulting scientific evidence. The myopic focus on the results in the form of data and peer-reviewed publications fails to recognize the labor, missteps, and, in some cases, consequential harms within the research process. I believe that this is a mistake. Peru has been central in building the scientific foundation to justify PrEP as a major intervention for gay and other MSM subjects and for transgender women in countries around the world. It is only by appreciating the on-the-ground actions necessary to obtain such evidence – such as interpreting who is classified as MSM and transgender women, creating strategies to convince people to participate and stay engaged in research, and navigating the competition between studies – that we can fully learn from them.

Final Thoughts

This dissertation examined the contemporary political economy surrounding HIV biomedical prevention research and the social production of scientific knowledge about certain people considered most at-risk – people categorized as MSM and transgender women. I have argued that the contemporary focus on HIV biomedical prevention and populations most at-risk must be understood in relation to the value that can be derived from these people categorized as MSM and transgender women. In doing so, we are able to acknowledge and reckon with the paradox of a system that “benefits from the very inequalities it aspires to redress” (Crane, 2013, p. 7).

By tracing the importation of the biomedical category “MSM,” Chapter 2 illustrated how the focus on sexual, and later gender, diversity helped structure Peru as an offshore biomedical research arena in line with the HIV industry’s broader agenda. Chapter 3 detailed the social processes within ongoing HIV prevention clinical trials that reinforce the commodification of particular identities to further fuel the value of data extraction among gender and sexually diverse communities. Chapter 4 looked closely at the HIV prevention research assembly line—from recruitment to enrollment to ongoing study procedures and, finally, study’s end – to make visible the extreme amount of work necessary to transform people into participants and participants into biological data to be delivered to the final customer: typically, global North researchers and/or funders.

The Peruvian case study demonstrates the particular role of risk data in the 4th decade of the HIV industry’s focus on prevention. It is these data on people categorized as MSM and transgender that are being arbitrated to fuel a growth industry around detailing risk and testing biomedical HIV prevention strategies. The implications from this analysis extend beyond Peru

and raise important questions relevant to other global sites where HIV prevention research is being offshored and conducted among marginalized and vulnerable communities. For example, what do we do with these data? Who benefits from them? Who is responsible for addressing vulnerability to HIV?

In response to these questions, I can imagine my biomedical colleagues replying, “We are creating scientific knowledge. *That* is our goal.” And I admit that the advances of the biomedical HIV prevention research industry, especially since 2010, are undeniably significant. Pre-exposure prophylaxis (PrEP) is the leading front-line strategy to therapeutically prevent HIV. However, this does not negate that creating this knowledge has also produced unintended yet very real harms. We are just at the beginning of PrEP research and implementation. Indeed, as I write this, clinical trials of long-acting PrEP in the form of injections and implants have recently begun. We must grapple with the entanglement of health research, prevention, and economic logics. In weighing the harms or potential harms of this research enterprise, we must also remember that that people who are the targets of HIV biomedical prevention are not yet sick. Only then will we be able to envision and enact solutions to address the underlying and often invisible exploitative practices that otherwise will continue to be replicated through PrEP scale-up and future HIV biomedical prevention science efforts.

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Appendix A

HIV Prevention Studies Observed

The following table provides information on the three HIV biomedical prevention research studies actively observed as part of my ethnographic fieldwork between February 2017 to February 2019. Included is a description of the funder, target population of focus, description of the study (drawn from publicly reported study aims), and my role on each of these studies. While pseudonyms are provided, and used throughout the study, readers with contextual knowledge of the Peruvian research landscape will undoubtedly be able to identify to which studies I am referring. Nonetheless, I use pseudonyms in an active effort to draw attention to the broader system within which HIV biomedical prevention research in Peru is conducted and its links to the global HIV research agenda, not an individual study.

<u>Study 1: PrEPTrans</u>
<p><i>PrEPTrans</i>, conducted between 2014 to 2019, was a US National Institutes of Health funded biomedical prevention social network-based intervention to promote PrEP adherence among transgender women in Lima, Peru. As a subcomponent of the intervention a pilot randomized controlled trial (RCT) was conducted, whereby 8 social network-based clusters of transgender women were randomized to either a network-based PrEP adherence intervention or standardized PrEP adherence counseling. The primary outcome was PrEP adherence and outcome was measured via self-report, blood samples, and hair samples. Specific to the RCT, conducted between September 2017 to July 2018, 172 transgender women were screened from 3 geographically distinct areas of Lima and 89 enrolled into 6 groups based on pre-existing social network clusters. I was Co-Investigator on this study and was part of the leadership team that designed and implemented this study.</p>

Study 2: Mujeres

The *Mujeres* (meaning women in English) study, conducted between 2014 to 2019, was funded by the American Foundation for AIDS Research. *Mujeres* was a non-randomized, single-arm, cohort study designed to assess the feasibility and acceptability of integrating routine HIV prevention and treatment services with gender-affirming care (i.e., feminizing hormone therapy) supported by transgender women community peer health navigators. It was designed to assess the feasibility and acceptability of a service delivery model designed to improve the HIV treatment and prevention cascades among transgender women in Lima, Peru by integrating HIV prevention and care services with gender-affirming transgender medical care. As part of this study, 200 transgender women were screened for study enrollment. Please note that the transgender organization *Mujeres* (with the same name as the research study) referenced throughout the dissertation was created as part of this research study. However, the organization formally became a community-based organization in 2018 and continues to operate even though the research study has concluded. I was a mixed-methods consultant for this study, primarily involved in the first phase of the study, conducted between 2016-2017.

Study 3: Combined screening for most at-risk (MSMComb)

MSMComb, conducted between 2014 to 2017 and funded by the US National Institutes of Health, assessed periodic counseling, testing, and treatment for rectal sexually transmitted infections by providing biological HIV prevention strategies for men who have sex with men (MSM) in Peru. Over 750 “behaviorally high-risk” MSM and 150 transgender women were screened for this study. Rectal gonorrheal and/or chlamydial (GC/CT) infected participants received single- dose antibiotic treatment and either single-session Personal Cognitive Counseling (PCC) (n=50) or standard post-test counseling (n=50). A GC/CT-negative control group (n=50) was also enrolled to compare biological outcomes including changes in levels of inflammatory cytokines following rectal STI. I had no official role on this study on the leadership team, but received approval to ethnographically observe. As such, I regularly attended lab and leadership team meetings and observed during recruitment events.

Appendix B

Informants Cited in Text

As noted in greater detail in the Introduction, between February 2017 through February 2019, I conducted a total of 110 in-depth semi-structured interviews. Interviews varied in length, ranging from 30 minutes to 2 hours and 35 mins. On average, they lasted approximately 1 hour and 30 minutes. Repeat interviews were also conducted through the ethnographic fieldwork period. Additionally, I conducted ten community discussions/focus groups which included 83 participants.

This dissertation followed the human subjects guidelines of Columbia University's Morningside Institutional Review Board (IRB) and the Universidad Peruana Cayetano Heredia (UPCH). IRBs at both institutions reviewed and approved all procedures for obtaining informed consent, protecting the anonymity of study participants and securing data. Through the data collection process and afterwards, careful measures were taken to ensure confidentiality. For example, personal identifiers were not attached to interviews (i.e., legal name, date of birth, etc.) and all participants were identified by unique pseudonyms rather than legal and/or social names. Additionally, all data collected was de-identified and saved on an encrypted and double password protected digital file and stored on an external hard drive.

After transcription, audio recordings of interviews were deleted and only unique pseudonyms were used in all field notes. Field notes that included identifiable information were destroyed. While unique pseudonyms were used to ensure confidentiality to study participants, key stakeholders may still be identifiable to readers with knowledge of the Peruvian context based on their leadership positions within well-known HIV research institutions. And in some

cases, such as, when referencing previously published material, real names (i.e., no pseudonyms) were used. In these cases, when identifiable key stakeholder quotes were used, I double checked quote with that individual and confirmed that they were willing to be specifically named as a key source in the dissemination of these data.

Below are descriptions of: (1) semi-structured interview participant characteristics, (2) community discussions/focus groups participant characteristics, and (3) details of informants cited in text.

Semi-structured interview participant characteristics (N= 110)		
	<i>N</i>	<i>%</i>
<i>Research Scientists</i>	33	
Peruvian	17	17.0
American	16	16.0
<i>Peruvian study staff</i>	17	
MDs and nurses	6	35.3
Peer recruiters	11	64.7
<i>Research Participants</i>	52	
MSM	22	42.3
Transgender women	30	57.7
<i>Other</i>	8	
US funder	3	37.5
US pharmaceutical representative	1	12.5
US medical students	4	50.0

Community discussions/focus groups participant characteristics (N=83)		
<i>Recruitment groups</i>	<i>Total participants</i>	<i>Within group composition</i>
<i>iPrEx and iPrEx OLE</i>	8	6 MSM; 2 transgender women
<i>iPrEx and iPrEx OLE</i>	10	7 MSM; 3 transgender women
<i>PrEPTrans</i>	7	All transgender women
<i>PrEPTrans</i>	8	All transgender women
<i>Mujeres</i>	12	All transgender women
<i>Mujeres</i>	10	All transgender women
Combined past HIV biomedical prevention research participants	11	7 MSM; 6 transgender women
Combined past HIV biomedical prevention research participants	7	3 MSM; 4 transgender women
<i>AMP</i>	8	6 MSM; 2 transgender women
Peer recruiters	12	6 MSM; 6 transgender women

Additionally, below is a table which includes an alphabetical list of all informants cited in the text. All of these informants were directly quoted and additional biographic information regarding these informants is included here. Please note that in order to protect the anonymity of informants, pseudonyms have been used throughout and some biographical data has been altered or withheld in order to ensure the privacy of informants. References to social class, sexuality, and/or gender identity are based on the informants' own classification. The only exceptions are quotes from Dr. Jorge Sánchez, primarily in Chapter 2, that detail the history of US funded training pathways from Peruvian investigators. In these cases, I double checked each quote with him to confirm its accuracy and his willingness to be specifically named as a key source in the dissemination of these data.

Informants Cited in Text:

Informant	Biographic description
Alexis	A 25-year-old Peruvian gay-identified study coordinator.
Blanca	Peruvian, self-identified <i>travesti</i> , who participated in PrEPTrans. She voiced interest in continuing on PrEP post-study end, however, noted that she would be unable to afford it.
Carlos	Peruvian, approximately 45 years old, and a peer-recruiter with over a decade of experience both working and participating in biomedical research. Carlos self-identifies as gay.
Christian	Peruvian attorney, in his early 50s, self-identified as gay, and an activist who has spent decades promoting generic medications for HIV treatment.

Dr. Alvarez	Peruvian Principal Investigator of an active US-funded HIV biomedical prevention study. Approximately 45 years old and trained as a physician at UPCH. Additionally, he was a Fogarty Fellow and obtained a US master's degree in public health.
Dr. Arizmendi	Peruvian expert, approximately 50 years old, with experience working on NIH-funded studies with transgender women. He received his medical degree from UPCH and an MPH in the US as a Fogarty Fellow.
Dr. Benavides	Peruvian researcher with prior experience as study coordinator across numerous US-funded HIV biomedical prevention studies. Approximately 39 years old and trained as a physician at UPCH. He also obtained a US master's degree in public health.
Dr. Benites	Peruvian HIV researcher and approximately 45 years old. Self-identifies as heterosexual and has worked on four large HIV biomedical prevention studies.
Dr. Black	American, approximately 55 years old, HPTN investigator has over 5 years of experience working in Peru.
Dr. Cruz	Peruvian physician-researcher, trained as medical doctor at UPCH, and previously worked at Impacta.
Dr. Delmonte	Peruvian biomedical researcher, trained as a medical doctor at UPCH and a Fogarty Fellow. Self-identifies as gay and has been Principle Investigator of three US-funded HIV biomedical prevention studies.
Dr. Dover	American physician-epidemiologist and NIH-funded investigator with active research projects that simultaneously include sites in Peru and the US.
Dr. Erikson	American public health researcher and NIH-funded investigator with active research projects in Peru.

Dr. Funegra	Peruvian physician-researcher, approximately 50 years old and trained as medical doctor at UPCH, and previously worked at Impacta.
Dr. Galvez	Peruvian physician researcher who works as a research coordinator for HPTN/HVTN studies in Lima.
Dr. Greene	An NIH program officer who actively manages grants HIV biomedical prevention grants conducted in Peru.
Dr. Jones	A prominent US physician researcher, NIH and HPTN/HVTN investigator with past research projects in Peru.
Dr. Lock	American physician-epidemiologist and principle investigator on HPTN 083.
Dr. Lucca	Peruvian physician-researcher, trained as medical doctor at UPCH, and HPTN/HVTN Principle Investigator.
Dr. Nelson	American physician with previous NIH R01 funding in Peru. Gay-identified and approximately 50 years old.
Dr. Paulson	American physician and NIH-funded investigator with past research projects in Peru.
Dr. Ruiz	Peruvian, in his late 50s, and former Peruvian public official dedicated to HIV policy.
Dr. Sánchez	Peruvian physician-researcher, trained at UPCH and Fogarty Fellow, and well-known leader in HIV biomedical research in Peru.
Dr. Smith	US physician and a top funded NIH biomedical scientist. He is in his late 60s and has been working in Peru for over 20 years.
Dr. Castellano	Peruvian research assistant, approximately 40 years old, trained in medicine at UPCH.
Elvira	Peruvian transgender woman in her late-20s. Engages in street-based sex work and primarily accesses HIV prevention and care through HIV biomedical research studies.
Emma	American PhD student conducting HIV biomedical prevention research focused on Peruvian transgender women.

Franco	Peruvian gay man, in his early 30s, former peer-recruiter for iPrEx and iPrEx OLE.
Giorgio	Peruvian self-described MSM, in his early 20s, and is an AMP study participant.
Hugo	Peruvian, gay identified and in his late 30s, HIV research coordinator with close to a decade of experience working on US-funded studies.
Jacko	Peruvian, gay identified, in his early 20s, and street-based male sex worker. Jacko was never before participated in research but voiced interest during recruitment session.
Jana	Peruvian transgender women approximately 40 years old and who works as a contract-based study recruiter for 2 ongoing HIV biomedical prevention studies.
Joaquin	Peruvian, gay peer recruiter, in his late 20s.
Juan Carlos	Peruvian, gay-identified study counselor, approximately 40 years old and has been working in HIV research for almost 2 decades.
Juan Pablo	Peruvian attorney and HIV treatment activist in his late 50s.
Juancito	Peruvian project coordinator with more than a decade of experience with HIV prevention research, has a Peruvian medical degree from UPCH and a US master's degree in epidemiology.
Julio	Peruvian self-identifies as a gay man and has participated in a total of four HIV biomedical studies.
Karla	Peruvian self-identified <i>travesti</i> , in her late 40s, and former iPrEx participant who declined participation in the two clinical trials I was observing.
Ken	Third-year US medical student and Fogarty fellow who conducted HIV biomedical research in Peru for a 10-month period. He is 26 years old and self-identifies as gay.

Lola	Peruvian self-identified <i>travesti</i> , in her early 20s, and street-based sex worker. Interested in participating in research to access HIV testing and condoms.
Lorena	Peruvian, self-identifies as a transgender woman, approximately 30 years old and works as a peer recruiter on 2 ongoing HIV biomedical prevention studies.
Luz	Peruvian, self-identifies as a transgender woman, in her late 20s and works as a peer recruiter.
Marisol	Peruvian self-identified transgender women, approximately in her late 20s, works as a brothel-based sex worker, and previously enrolled in PrEPTrans but discontinued participation in study.
Miguel	Peruvian self-identified gay, in his early 50s, and frequent study participant.
Nikki	Peruvian, self-identified <i>travesti</i> who became involved in research through participation and now works as a peer recruiter. She is in her late 40s.
Paco	Peruvian, self-identified gay man and gay-activist, approximately 50 years old. He was involved in early NAMRU and UPCH efforts to test gay men for HIV.
Pancho Hidalgo	Peruvian, in his late 50s, self-identified as gay and has over 2 decades working in HIV research.
Paquita	Peruvian, cisgender woman and self-identified as heterosexual, she is in her late 30s and works as a study coordinator for an HIV biomedical prevention study targeting transgender women.
Pedro	Peruvian and about 25 years old. He was born and raised in Lima and has been working as a peer recruiter for about 5 years. In addition, he participated in iPrEx but now prefers to work for research studies versus participating in them.

Ricardo	Peruvian self-identified as heterosexual, approximately 35 years old, cisgender, and a study counselor for an ongoing HIV biomedical prevention study focused on MSM and transgender women.
Roberto	Peruvian self-identified as gay and is a study coordinator with more than a decade of experience working on US-funded research focused on MSM and transgender women.
Rocio	Peruvian, cisgender and self-identified as heterosexual. She is a research nurse and approximately 40 years old.
Sasha	Peruvian, self-identified transgender woman who enrolled in 4 studies but has chosen to no longer participate in research. She is in her late 40s.
Yaiza	Peruvian, self-identified transgender women, who has been working as a peer-recruiter for approximately 5 years. She is in her late 30s and also works as a sex-worker.
Yasmin Costas	Peruvian, self-identified transgender women, who is in her early 30s. She is a clinical trial staff member, well-known trans <i>madre</i> , and also considers herself a feminist and activist.

Appendix C

Acronym Glossary

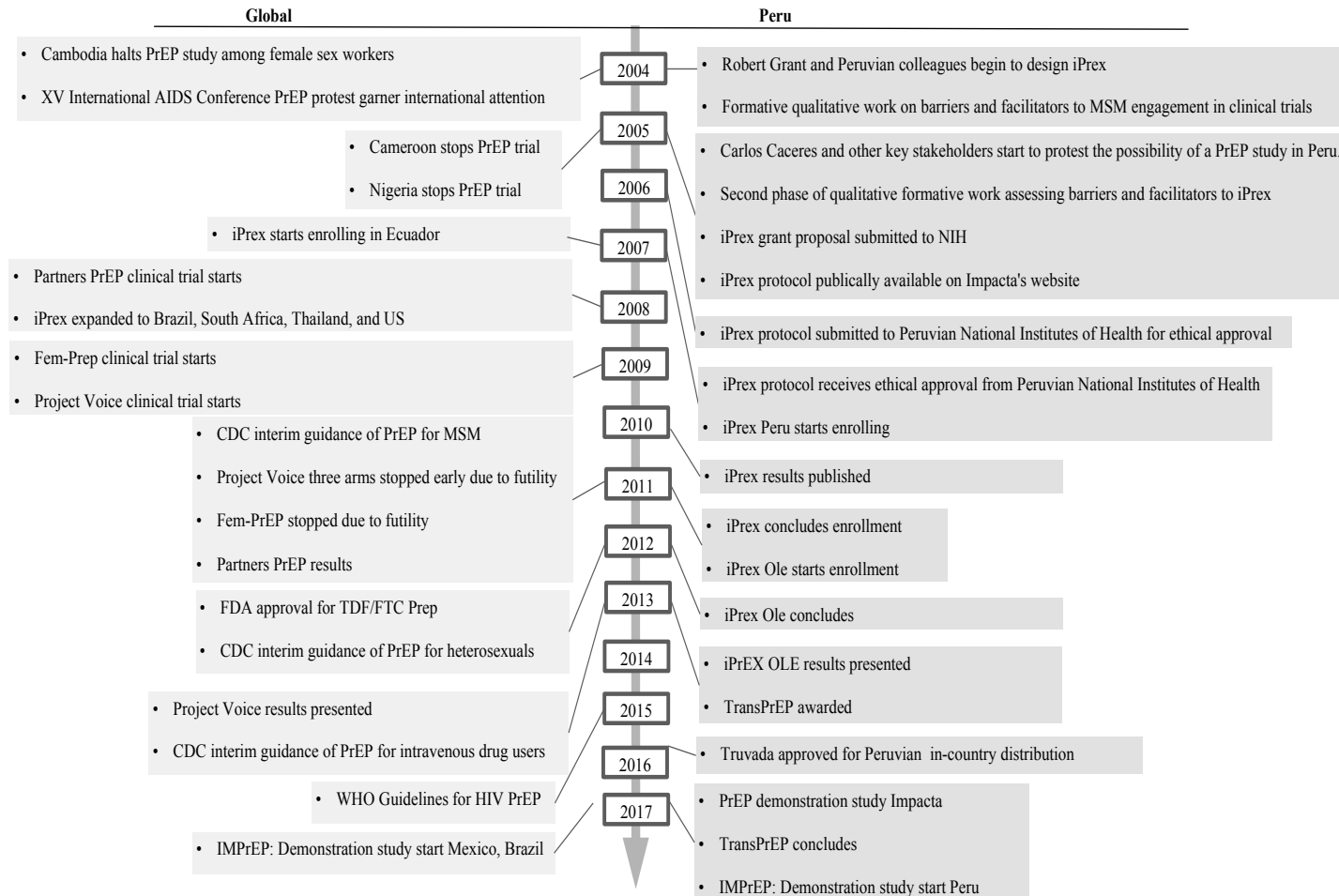
Acronym	Referent
ACTG	AIDS Clinical Trials Group
ACTG 076	The AIDS Clinical Trials Group Study 076 was a Phase III, randomized, double-blind, placebo-controlled clinical trial, designed to evaluate whether zidovudine (AZT) administered to HIV-infected pregnant women and their infants could reduce the rate of transmission from mother to infant.
AIDS	Acquired Immune Deficiency Syndrome
amfAR	American Medical Research Foundation
AMP	Stands for Antibody Mediated Prevention, also referred to as HVTN 704/HPTN 085. It is a clinical trial to test whether giving people an investigational anti-HIV antibody called VRC01 as an intravenous infusion every 8 weeks is safe, tolerable and effective at preventing HIV infection.
ARV	Antiretroviral Therapy
AZT	Zidovudine
CAB	Community advisory board
CDC	Centers of Disease Control
CPOL	The first US-funded large-scale randomized trial among MSM conducted in Peru (PI: Cáceres). CPOL stand for community-level popular opinion leaders.
CRO	Contract research organization
DNI	Documento nacional de identidad "Peruvian national identity document"
FDA	US Food and Drug Administration
FIC	Fogarty International Center
GDP	Gross Domestic Product

HIV	Human Immunodeficiency Virus Infection
HPTN	HIV Prevention Trials Network
HVTN	HIV Vaccine Trials Network
ICOHRTA	US-funded training grant was the International Clinical, Operational, and Health Services Research Training Award for AIDS and Tuberculosis
IMF	International Monetary Fund
iPrEx	From Spanish, Iniciativa Profilaxis Pre-Exposición (pre-exposure prophylaxis initiative) a phase III clinical trial conducted between 2007 and 2010.
iPrEx OLE	Open label extension of iPrEx
IRB	Institutional Review Board
IRGT	The International Reference Group on Transgender Women and HIV/AIDS
LGBTQ	Lesbian, Gay, Bisexual, Transgender, and Queer
LSE	London Stock Exchange
MARP	Most-at-risk populations
MHOL	El Movimiento Homosexual de Lima "homosexual movement of Lima"
MSM	Men who have sex with men and many not identify as gay
MSMGF	The Global Forum on MSM and HIV
NAMRID	US Navy Medical Research Institute Detachment
NGO	Non-governmental organization
NIH	National Institutes of Health
PARACAS	The Program for Advanced Research Capacities for AIDS
PECOS	Programa Especial de Control del Sida "Special Program for the Control of AIDS "
PEPFAR	The President's Emergency Plan for AIDS Relief
PI	Principal Investigator
PrEP	Pre-exposure prophylaxis
PREVEN	A US-funded large community-randomized clinical trial (PI: Garcia) conducted across 20 Peruvian cities that assessed the effects of numerous

	prevention modalities on various sexually transmitted infectious, including HIV.
PROCETSS	Programa de Control de Enfermedades de Transmisión Sexual y Sida "Program for the Control of Sexually Transmitted Diseases and AIDS"
SFAF	San Francisco AIDS Foundation
STS	Science and Technology Studies
TW	Transgender women
UA	University of Alabama
UCLA	University of California, Los Angeles
UCSF	University of California, San Francisco
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNESCO	The United Nations Educational, Scientific and Cultural Organization
UNGASS	The United Nations General Assembly Special Session
UPCH	Universidad Peruana Cayetano Heredia
USAID	The United States Agency for International Development
USD	United States Dollar
UW	University of Washington
VRC01	A broadly neutralizing antibody targeting HIV's CD4 binding site and able to modestly delay the return of viral replication following interruption of antiretroviral therapy. Therapeutic prevention treatment tested in the AMP study.
WHO	World Health Organization

Appendix D:

Timeline of Notable Events in PrEP Research and Dissemination, Globally and in Peru



Appendix E:

NIH Reported Data on Peruvian Scientist Lead Grant Awards

Project Title	NIH Institute	Project Number	Contact PI / Project Leader	FY Total Cost
Training in Infectious Diseases in Peru – Time for Capacity Strengthening in Clinical Research	FIC	D43TW001140	Hector Hugo Garcia	3,738,406
Development ITMAvH-UAB-ITMA Comprehensive ICOHRTA-AIDS	FIC	R21TW006114	Eduardo Gotuzzo	81,000
Feasibility of CBVCT in Lima Peru	NIAID	R03AI058811-01A1	Sixto Sánchez	107,995
HIV Pathogenesis, prevention and treatment in the Andes	NIAID	R03AI051671	Jorge Sánchez	3,038,234
Peru Infectious Diseases Epidemiology Research Training Consortium	FIC	D43TW007393	Andres Lescano/ David Blazis	3,612,509
Evaluating Population Impacts of HIV/STD Interventions	NIAID	U19AI053218	Patricia Garcia	179,000
Evaluation of a Computer-Based System using Cell	FIC	R01TW007896	Walter Curioso	152,280

Phones for HIV people in Peru				
Peru ICOHRTA Network for AIDS/TB Research Training	FIC	U2RTW007368	Eduardo Gotuzzo	1,804,649
Impacta Peru Clinical Trials Unit	NIAID	UM1AI069438	Jorge Sánchez	24,859,028
A Step Forward for a Latin American AIDS Research and Training Program (LAARTP)	FIC	D43TW008069	Jorge Sánchez	49,680
QUIPU: The Andean Global Health Informatics Research and Training Center	FIC	D43TW008438	Patricia Garcia	1,308,715
Randomized controlled trial to evaluate the effect of a novel web-based intervention	FIC	R01TW008398	Magaly Blas	160,920
Syphilis: Translating technology to understand a neglected epidemic	NIAID	5R01AI099727	Carlos Caceres	1,082,833
Developing a State-of-the-Art Combination HIV Prevention Program for MSM/Transgender women	NIMH	R21MH102135	Carlos Caceres	296,940
Planning a Strategic HIV Population Science Training Grant in Peru	FIC	D71TW009611	Carlos Caceres	60,480

Kuskaya: An Interdisciplinary Training Program for Innovation in Global Health	FIC	D43TW009375	Patricia Garcia/ Magaly Blas	1,625,983
PARACAS: Program for Advanced Research Capacities for AIDS in Peru	FIC	D43TW009763	Eduardo Gotuzzo	1,319,080
TOTAL:	43,477,732			