Copyright

by

Jonathan Banda

2015

# The Thesis Committee for Jonathan Banda Certifies that this is the approved version of the following thesis:

# Biomedicalizing Risk: Technologies of HIV Prevention and the Moral Imperatives of Biological Citizenship

	Committee:
	Rebecca Hester, Supervisor/Chair
	Arlene MacDonald
	Joan Nichols
Dean, Graduate School	

# Biomedicalizing Risk: Technologies of HIV Prevention and the Moral Imperatives of Biological Citizenship

# by

## Jonathan Paul Banda, BA, BS

### **Thesis**

Presented to the Faculty of the Graduate School of

The University of Texas Medical Branch
in Partial Fulfillment
of the Requirements
for the Degree of

**Master of Arts, Medical Humanities** 

The University of Texas Medical Branch
July 2015

## Acknowledgments

Chapters 1 and 2 of this thesis are based on an earlier version of a paper published in the journal *Body & Society*. The final, definitive version of this paper has been published in *Body & Society* as "Rapid Home HIV Testing: Risk and the Moral Imperatives of Biological Citizenship," prepublished July 21, 2014, DOI:10.1177/1357034X14528391. I retain copyright to this publication as sole author. I would like to thank the anonymous reviewers and editorial board at *Body & Society* for their close review and critique of previous versions of this article. I would like to thank the faculty and my fellow students at the Institute for the Medical Humanities for their comments on earlier presentations of this work and support over the past several years. I would like to thank the members of my committee, Professors Rebecca Hester, Arlene Macdonald, and Joan Nichols. Words escape me to express how much I appreciate your encouragement and feedback throughout the process of compiling this thesis.

# Biomedicalizing Risk: Technologies of HIV Prevention and the Moral Imperatives of Biological Citizenship

<b>Publication</b>	No.
--------------------	-----

Jonathan Banda, MA, Medical Humanities
The University of Texas Medical Branch, 2015

Supervisor: Rebecca Hester

This thesis examines the history and social implications of the rapid self-test for human immunodeficiency virus (HIV) in the United States. Via a discursive analysis of literature, product packaging, and marketing and public health rhetoric surrounding the test (brand name: OraQuick in-home HIV test), I identify several points of contention that have arisen with the varied, sometimes disparate interests of public health, federal regulators, and private corporations. I propose that while home HIV tests may improve health outcomes for some and appear to expand consumer rights, they are in fact the vanguard of a new form of self-testing that carries a moral urgency to protect one's own body and to manage societal risk. This thesis concludes with a critical analysis of the prophylactic use of antiretrovirals for HIV, arguing that this practice represents a new relation of the body to risk, while potentially obscuring or normalizing structural conditions that contribute to vulnerability to infection.

# TABLE OF CONTENTS

Table of Contents	vi
List of Abbreviations	vi
Introduction	8
Critique and Sexual Politics	10
A Matter of "Life Itself": Theories of Biopolitics	11
Biomedicalization and Risk Theory	15
The Biopolitics of Security	20
Resilient Subjects	24
Methodology and Project Outline	26
CHAPTER 1: HOME RAPID HIV TESTING AND PRACTICES OF CITIZENSHIP	28
Home HIV Tests and the Construction of Biological Citizens	31
Symbolic Demedicalization	36
Stratified Biomedicalization	40
CHAPTER 2: RISK AND THE UNTESTED BODY	43
HIV Self-Testing and the Construction of "Risky" Bodies	44
Surveillance of Self and Others	46
Somatic Ethics and Partner Screening for HIV	48
CONCLUSION: CHEMOPROPHYLAXIS FOR HIV AND THE RESILIENT BODY	53
PrEP and the Construction of Biological Citizens	53
Resilient Subjects to Resilient Bodies	58
Questioning the "Truth" of PrEP and HIV Self-Testing	61
EPILOGUE	66
Bibliography	69

## **List of Abbreviations**

AIDS Acquired Immune Deficiency Syndrome

BPAC Blood Products Advisory Committee

CDC Centers for Disease Control and Prevention

FDA Food and Drug Administration

GLBT Gay, Lesbian, Bisexual, and Transgender

GSBS Graduate School of Biomedical Science

HIV Human Immunodeficiency Virus

NIH National Institutes of Health

UTMB University of Texas Medical Branch

#### Introduction

Despite our best efforts, achieving a complete state of critical infrastructure and key resources protection is not possible in the face of the numerous and varied catastrophic possibilities that could challenge the security of America today. Recognizing that the future is uncertain and that we cannot envision or prepare for every potential threat, we must understand and accept a certain level of risk as a permanent condition.

United States Department of Homeland Security<sup>1</sup>

The politics of truth pertains to those relations of power that circumscribe in advance what will and will not count as truth, which order the world in certain regular and regulatable ways, and which we come to accept as the given field of knowledge. We can understand the salience of this point when we begin to ask: What counts as a person? ... What qualifies as a citizen? Whose world is legitimated as real? Subjectively, we ask: Who can I become in such a world where the meanings and limits of the subject are set out in advance for me? By what norms am I constrained as I begin to ask what I may become?

Judith Butler<sup>2</sup>

Ursula K. Le Guin's 1975 philosophical fiction "The Ones Who Walk Away from Omelas" resonates profoundly with the workings of contemporary politics, and in particular, the politics of medicine and health.<sup>3</sup> To summarize briefly: Le Guin begins her narrative by describing the first day of summer in the city of Omelas. The residents are celebrating the Festival of Summer, but it seems that every day is a reason to rejoice, as joy and pleasure are the norm. There is no king over the city; the residents appear to

<sup>&</sup>lt;sup>1</sup> Homeland Security Council, *National Strategy for Homeland Security* (Washington, DC: Homeland Security Council, 2007), 25, accessed July 4, 2015, http://www.dhs.gov/xlibrary/assets/nat\_strat\_homelandsecurity\_2007.pdf.

<sup>&</sup>lt;sup>2</sup> Judith Butler, "What Is Critique? An Essay on Foucault's Virtue," *Transversal* (May 2001): paragraph 29, accessed July 4, 2015, http://eipcp.net/transversal/0806/butler/en.

<sup>&</sup>lt;sup>3</sup> Ursula Le Guin, "The Ones Who Walk Away from Omelas," in *The Wind's Twelve Quarters* (New York, NY: Harpers & Row, 1975), 275-284.

govern themselves. There are no slaves, swords, or soldiers. The citizens feel victorious without guilt, for it is life itself they celebrate.

However, such joy is not a universal condition in Omelas. As the celebration of life continues outside, readers find a small windowless room in the basement of one of the city's beautiful buildings, its door locked. In the room sits a child of about ten years, described as "feeble-minded," emaciated, covered with sores as a result of having to sit in his/her own excrement. The child lives in constant terror, and no one visits, except for those who periodically bring the meager amounts of food and water on which the child survives. Le Guin explains:

They all know it is there, all the people of Omelas. Some of them have come to see it, others are content merely to know it is there. They all know that it has to be there. Some of them understand why, and some do not, but they all understand that their happiness, the beauty of their city, the tenderness of their friendships, the health of their children, the wisdom of their scholars, the skill of their makers, even the abundance of their harvest and the kindly weathers of their skies, depend wholly on this child's abominable misery.<sup>4</sup>

In *Economies of Abandonment*, anthropologist Elizabeth Povinelli argues that Le Guin's story "opens a productive avenue for critically engaging the affective attachments and practical relationships of subjects to the unequal distribution of life and death, of hope and harm, and of endurance and exhaustion in late liberalism." The work in this thesis engages with the politics of life and death by critically examining several novel technologies of HIV/AIDS prevention in the United States: the rapid HIV self-test, which is the primary focus of this analysis, and pre-exposure prophylaxis (PrEP), which I will discuss in the conclusion as a future line of research.

<sup>&</sup>lt;sup>4</sup> LeGuin, "The Ones Who Walk Away from Omelas," 282.

<sup>&</sup>lt;sup>5</sup> Elizabeth Povinelli, *Economies of Abandonment: Social Belonging and Endurance in Late Liberalism* (Durham, NC: Duke University Press Books, 2011), 3.

#### **CRITIQUE AND SEXUAL POLITICS**

This thesis offers a critique of HIV/AIDS prevention strategies and of biomedicine more broadly. With critique, I engage with a long tradition of scholarship in the social sciences and humanities that has questioned various forms of knowledge accepted as truth and the practices they engender. For those who engage in critique, Judith Butler argues, "not only is it necessary to isolate and identify the peculiar nexus of power and knowledge that gives rise to the field of intelligible things, but also to track the way in which that field meets its breaking point, the moments of its discontinuities, the sites where it fails to constitute the intelligibility for which it stands." My analysis, therefore, is concerned with the lack of coherence within public health interventions, as the interests of public health and neoliberal capitalism converge. These contested spaces are central to my analysis, since they reveal the "breaking points" of contemporary US health politics: in such circumstances, the promises of new medical technologies to improve health outcomes (promises that are also the justification for their market approvals) are often diminished on the ground by the competing interests of private, profit-driven corporations.

These health outcomes themselves are no less problematic, for in the imperative of health, only certain lives, or ways of living, are valued, while others are made deviant or pathological. As a queer minority growing up in the era of HIV/AIDS, I embodied public health rhetoric regarding HIV/AIDS and the dangers of certain sexual practices, which seemed commonsensical. Sex, fear, and death became inextricably intertwined. My investment in this project, therefore, is not neutral. As I have come to realize, however, neither are the projects of medicine and public health. Historically, infectious diseases, and particularly those transmitted sexually, have been productive sites for the disciplining of sexual behavior and reinforcing social norms and stigma, which in turn

<sup>&</sup>lt;sup>6</sup> Butler, "What Is Critique?" paragraph 35.

has fueled the disenfranchisement of populations who are seen as threats to the welfare of the collective society. As political scientist James Morone has observed: "The myth of a liberal society makes it easy to overlook moral boundaries and the ways we use them [...] Apparent efforts to improve public health—alcohol prohibition, drug wars, campaigns against sexually transmitted diseases—often turn into ways of dividing American society, of sorting out the moral us from the threatening them." Thus, my analysis looks at HIV prevention technologies not only as practices of citizenship, but also as dividing practices in society, practices that distinguish the tested from the untested, and those who have HIV from those who have escaped its grasp thus far. As follows, this introduction tracks the theoretical foundations for the analysis in this thesis:

1) Foucault's exposition on biopolitics, 2) biomedicalization theory, 3) social theories of risk, and 4) critiques of security and resilience.

#### A MATTER OF "LIFE ITSELF": THEORIES OF BIOPOLITICS

The theoretical background for this analysis is rooted in the work of Michel Foucault on biopolitics. Foucault uses the term *biopower* to describe the transformation in the basis for governance in the West, beginning in the eighteenth century, from the sovereign's right "to take life or let live," to the social body's right "to foster life or disallow it to the point of death." Biopower, he notes, "is situated and exercised at the level of life, the species, the race, and the large-scale phenomena of the population," and was facilitated by the development of statistical science. In the first volume of *The History of Sexuality*, Foucault identifies two forms of biopower: "an anatomo-politics of

<sup>&</sup>lt;sup>7</sup> My analysis will focus on strategies to reduce the sexual transmission of HIV/AIDS; interventions that address other transmission methods (i.e., sharing of needles and mother-to-child transmission), while also problematic, are outside the scope of this project.

<sup>&</sup>lt;sup>8</sup> James A. Morone, "Enemies of the People: The Moral Dimension to Public Health," *Journal of Health Politics, Policy and Law.* 22, no. 4 (August 1997): 1015.

<sup>&</sup>lt;sup>9</sup> Michel Foucault, *The History of Sexuality*, vol. 1, trans. Robert Hurley (New York, NY: Vintage, 1980), 136-138.

<sup>&</sup>lt;sup>10</sup> Ibid., 137.

the human body," or disciplinary power, and "regulatory controls," which he calls "a *biopolitics* of the population." Whereas before the emergence of biopower biological life could be separated from politics, this new form of power "places [man's] existence as a living being in question," and, therefore, there is no life that is excluded from the realm of biopolitics, which subsumes the biological existence of the population under its domain. <sup>12</sup> In other words, modern politics is a matter of "life itself." <sup>13</sup>

What emerges, according to Foucault, is a thanatopolitical paradox: biopower not only fosters life, but also negates it to the point of death. Sovereign power relied on the capacity to kill. With biopower, however, the extermination of life "presents itself as the counterpart of a power that exerts a positive influence on life." In *Society Must Be Defended*, Foucault asks: "Given that this power's objective is essentially to make live, how can it let die? How can the power of death, the function of death, be exercised in a political system centered upon biopower?" According to Foucault, it is here that racism intervenes. Racism is what divides the lives that will be fostered from those that will be killed or disallowed to the point of death, which includes both biological and political/social death. He sums up the logic this way:

'The more inferior species die out, the more abnormal individuals are eliminated, the fewer degenerates there will be in the species as a whole, and the more I—as a species rather than individual—can live, the stronger I will be, the more vigorous I will be. I will be able to proliferate.' The fact that the other dies does not mean simply that I live in the sense that his death guarantees my safety; the death of the other, the death of the bad race, of the inferior race (or the degenerate or the abnormal) is something that will make life in general healthier: healthier and purer.<sup>16</sup>

<sup>&</sup>lt;sup>11</sup> Ibid., 139. Italics mine.

<sup>&</sup>lt;sup>12</sup> Ibid., 142.

<sup>&</sup>lt;sup>13</sup> Michel Foucault, *The Order of Things: An Archaeology of the Human Sciences* (London, UK: Tavistock Publications, 1970), 128.

<sup>&</sup>lt;sup>14</sup> Ibid., 137.

<sup>&</sup>lt;sup>15</sup> Michel Foucault, "Society Must Be Defended": Lectures at the Collège de France, 1975-1976, trans. David Macey (London, UK: Penguin, 2003), 254.

<sup>&</sup>lt;sup>16</sup> Ibid., 255.

Racism, as used here, is against those who, for whatever reason, fail to live up to dominant societal norms, including the imperative of health. Viewing public health efforts, such as HIV testing, as biopolitical regimes forces us to grapple with how measures aimed to produce positive health outcomes for some can also exacerbate the suffering of others by exclusionary and dividing practices.

This current analysis on HIV testing will use the work of sociologist Nikolas Rose as its main theoretical influence. In *The Politics of Life Itself*, Rose claims that contemporary biopolitics has led to a certain degree of "biologization of the human soul," and its subjects have increasingly come to see themselves as "somatic" individuals "who experience, articulate, judge, and act upon ourselves in part in the language of biomedicine . . . our corporeality, now at the molecular level, is the target of our judgments and of the techniques that we use to improve ourselves." Political/social life (*bios*) has now been folded into the biological (*zoë*). Biomedicine today views and understands life at the molecular level; thus, biotechnologies can act upon and transform "life itself."

Nikolas Rose and Carlos Novas also argue that contemporary biopolitics has engendered a new form of citizenship: biological citizenship. <sup>19</sup> This form of citizenship no longer emphasizes national identity; instead, it emphasizes the biological understanding of the body and human existence and the ways that understanding links individuals to others and distinguishes them from noncitizens. Continuous monitoring of one's health is an expectation and obligation of each biological citizen. As Rose observed in his earlier work on governmentality and the liberal state, the subjects of government in advanced liberal societies are envisioned as "creatures of freedom, liberty, and autonomy" and are expected to govern the self by becoming "experts of themselves"

<sup>&</sup>lt;sup>17</sup> Nikolas Rose, *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century* (Princeton, NJ: Princeton University Press, 2007), 25-26.

<sup>&</sup>lt;sup>18</sup> Ibid., 12.

<sup>&</sup>lt;sup>19</sup> Nikolas Rose and Carlos Novas, "Biological Citizenship," in *Global Assemblages*, ed. Aihwa Ong and Stephen J. Collier (Oxford, UK: Blackwell Publishing, 2004), 439-462.

via methods of self-care and behavior modification.<sup>20</sup> Health promotion and education, in their various forms, are part of an effort to construct citizens from above, shaping the way they see their bodies and their obligations to themselves and those around them.

Rose considers the "making up" of biocitizens from above via health promotion, public education regarding science and technology, and pharmaceutical marketing and outreach. However, he also notes that one should not only consider the construction of citizens from above. Biological citizens are expected to be active and enterprising regarding their health: "to be flexible, to be in continuous training, life-long learning, to undergo perpetual assessment, continual incitement to buy, constantly to improve oneself, to monitor our health, to manage our risk."<sup>21</sup> Therefore, in addition to being produced from above, the biocitizen appears to be actively involved in forming him/herself from below. Much of the literature to date on biocitizenship in relation to HIV emphasizes its collectivizing, active force and the formation of politically motivated biosocieties.<sup>22</sup> However, my interests situate HIV self-testing and other preventive technologies as individualizing acts that, while entailing responsibilities to others, also serve as dividing practices; the practice of self-testing divides by serostatus and separates the tested from the untested, both at the individual and population levels. In addition, I wish to address a particular form of biocitizenship that is often ignored: the inactive citizen.

\_

<sup>&</sup>lt;sup>20</sup> Nikolas Rose, "Governing 'Advanced' Liberal Democracies," in *Foucault and Political Reason*, ed. Andrew Barry, Thomas Osbourne, and Nikolas Rose (Chicago, IL: University of Chicago Press 1996), 59. Also see Michel Foucault, "The Subject and Power," *Critical Inquiry* 8, no. 4 (Summer 1982): 777-795.

<sup>&</sup>lt;sup>21</sup> Ibid., 154.

<sup>&</sup>lt;sup>22</sup> For example, see Vinh-Kim Nguyen, "Antiretroviral Globalism, Biopolitics, and Therapeutic Citizenship," in *Global Assemblages*, ed. Aihwa Ong and Stephen J. Collier (Oxford, UK: Blackwell, 2004), 124–144.

#### BIOMEDICALIZATION AND RISK THEORY

Rose appears to minimize the thanatopolitical paradox in Foucault's work. "While biopower, today, certainly has its circuits of exclusion," he observes, "letting die is not making die. This is not a politics of death, though death suffuses and haunts it . . . it is a matter of the government of life." He acknowledges the differential value assigned to forms of life, for example, the vast differences in life expectancy between nations. Certainly a case of "letting die," Rose concludes, but he cannot reconcile it with a biopolitical rationale—the fact that a person in Malawi has a life expectancy of thirtynine, he argues, does not improve the (somatic) quality of a population to meet national objectives. Because Rose privileges biomedicine as the framework for contemporary politics, he does not consider other rationales for "letting die" (for example, national security), nor that there are populations without access to the resources required to "enterprise themselves" via biomedicine. It is my intent to complicate the concept of biological citizenship and account for its exclusionary tendencies by also engaging (bio)medicalization theory and risk theory.

Medicalization as a theoretical concept emerged in the 1970s among social scientists as one framework for the critique of medicine and its role in society. Sociologist Peter Conrad, one of the more prominent theorists of medicalization, describes the concept as

defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to "treat" it. This is a sociocultural process that may or may not involve the medical profession, lead to medical social control or medical treatment, or be the result of intentional expansion by the medical profession. *Medicalization occurs when a medical frame or definition has been applied to understand or manage a problem.*...<sup>24</sup>

<sup>&</sup>lt;sup>23</sup> Rose, *The Politics of Life Itself*, 70.

<sup>&</sup>lt;sup>24</sup> Peter Conrad, "Medicalization and Social Control," *Annual Review of Sociology* 18, no. 1 (1992): 211. Italics mine.

The process of medicalization, therefore, does not rely exclusively on the medical profession to gain traction in society; as a sociocultural phenomenon, a host of social actors can be implicated in its emergence, depending on the problem being medicalized.

Adele Clarke and her colleagues use the term biomedicalization to describe the intensification of medicalization using technoscientific innovations, including new medical technologies, since the mid-1980s. Their central argument is that contemporary biomedicine is "being transformed from the inside out through old and new social arrangements that implement biomedical, computer, and information sciences and technologies to intervene in health, illness, healing, the organization of medical care, and how we think about and live 'life itself." As will become clear from my analysis in this thesis, one of the major problems that HIV testing and prevention strategies attempt to manage is "life itself," the object of biopolitics.

Clarke and colleagues are careful to acknowledge the unequal access to new technologies and innovations of biomedicalization that exists across populations and the ways these interventions may actually exacerbate inequalities, despite their stated goals of health promotion. In fact, they argue:

Exclusion, inclusion, and the embeddedness of race, class, gender, and other sites of inequality dwell in the very structures and processes of biomedicalization—in the very ways that technoscience is itself inherently social. Thus biomedicalization carries within itself the ideological, social, and cultural infrastructures that support and maintain racial and class inequalities.<sup>26</sup>

Such is the very nature of biopolitics; in the words of Elizabeth Povinelli, the biopolitical is "not a space of life but a spacing of life, not a living difference but a difference within the living."<sup>27</sup>

<sup>&</sup>lt;sup>25</sup> Adele E. Clarke, Janet K Shim, Laura Mamo, Jennifer Ruth Fosket, and Jennifer R. Fishman. "Biomedicalization: A Theoretical and Substantive Introduction," in *Biomedicalization: Technoscience*, Health, and Illness in the U.S., ed. Adele Clarke, Janet K Shim, Laura Mamo, Jennifer Ruth Fosket, and Jennifer R. Fishman (Durham, NC: Duke University Press, 2010), 2.

<sup>&</sup>lt;sup>27</sup> Povinelli, Economies of Abandonment, 109.

Assessing and categorizing risk constitute one of the most potent methods by which neoliberal societies ascribe differential value to the living. Theories of risk in the social sciences and humanities range from realist perspectives, which take risk as an external threat that can be measured objectively (though it may be distorted by socialcultural influences), to weak constructivist perspectives, which see risk as an objective phenomenon that is always mediated (and inseparable from) socio-cultural influences, and to strong constructivist perspectives that seem to deny that there is any objective risk in and of itself, but that risks are always historically contingent, and their existence depends entirely on sociocultural perceptions.<sup>28</sup> In this analysis, I aim to avoid the realist vs. social constructivist dichotomy—that is, risks are both socially constructed and material entities. I concur with sociologist Deborah Lupton, who recently observed: "Risks are always virtual, in the process of becoming: they are potentialities, both 'constructed realities' and 'real constructions' that are comprised of complex networks of materialities, procedures, regulations, discourses and strategies—and emotions."<sup>29</sup> My approach also recognizes that the higher risks that many face across the globe are indeed constructed from material conditions that arise from histories of structural violence and inequities.<sup>30</sup> Such populations, therefore, are more likely to suffer from disease and other conditions, which, in turn, undeniably have material consequences on their lives.

Nikolas Rose characterizes contemporary biopolitics in part as a "risk politics," defining *risk* as: "a family of ways of thinking and acting, involving calculations about probable futures in the present followed by interventions into the present in order to control that potential future."<sup>31</sup> Contemporary biopolitical strategies, he notes, attempt to

<sup>28</sup> Deborah Lupton, *Risk*, 2<sup>nd</sup> ed. (New York, NY: Routledge, 1999), 35.

<sup>&</sup>lt;sup>29</sup> Deborah Lupton, "Risk and Emotion: Towards an Alternative Theoretical Perspective," *Health, Risk & Society* 15, no. 8 (2013): 638.

<sup>&</sup>lt;sup>30</sup> Paul Farmer, "An Anthropology of Structural Violence," *Current Anthropology*, 45, no. 3 (June 2004): 305-317.

<sup>&</sup>lt;sup>31</sup> Nikolas Rose, "The Politics of Life Itself," *Theory, Culture, and Society* 18, no. 6 (December 2001): 7.

identify those individuals and populations at risk of pathologies or undesirable conditions, with the intent to manage these populations or minimize the effects of their pathologies. Rose argues that this strategy is distinct from eugenic strategies of the past century, which sought to eliminate the defective members of society. Instead, he argues, the goal of today's biopolitics: "is that of pre-symptomatic diagnosis followed by technical intervention at the biological level to repair or even improve the sub-optimal organism." Nevertheless, even Rose must acknowledge the "circuits of exclusion" of such biopolitical strategies.

As Lupton notes, when risks are seemingly open to human modification, individuals who are believed to be "at risk" are blamed for their condition and "become the sinners, not the sinned against, because of their apparent voluntary courting of risk." However, with the shift to biomedicalization, to be "at risk" has become a generalized condition; risk assessments today do not seek to simply identify those who are at risk but instead aim to distinguish individual levels of risk within a population. As Clarke and colleagues observe:

It is no longer necessary to manifest to be considered ill or "at risk." With the "problematization of the normal" and what Armstrong (1995) calls "surveillance medicine," everyone is implicated in the process of eventually "becoming ill." Both individually and collectively, we inhabit tenuous and liminal spaces between illness and health leading to the emergence of the "worried well," rendering us ready subjects for health-related discourses, commodities, services, procedures and technologies. It is impossible not to be "at risk."<sup>35</sup>

In this context, what distinguishes individuals, therefore, is not *whether* they are at risk, but *the extent* of their risk in relation to others. Such risk categorizations are assessed using various factors, including (and often privileging, as in the case of HIV) one's

33 Ibid.

<sup>&</sup>lt;sup>32</sup> Ibid., 21.

<sup>&</sup>lt;sup>34</sup> Deborah Lupton, "Risk as Moral Danger: the Social and Political Functions of Risk Discourse in Public Health," *International Journal of Health Services* 23, no. 3 (July 1993): 429.

<sup>&</sup>lt;sup>35</sup> Adele E. Clarke, Janet K Shim, Laura Mamo, Jennifer Ruth Fosket, and Jennifer R. Fishman. "Biomedicalization: Technoscientific Transformations of Health, Illness, and U.S Biomedicine," in *Biomedicalization: Technoscience, Health, and Illness in the U.S.*, ed. Adele Clarke, Janet K Shim, Laura Mamo, Jennifer Ruth Fosket, and Jennifer R. Fishman (Durham, NC: Duke University Press, 2010), 64.

behavior and very form of life. Despite their ostensibly objective nature, these assessments often reflect existing societal divisions, for example, along the lines of race, class, sexuality, and gender.

Since its emergence in the 1980s, the classification of certain groups as high-risk for HIV/AIDS mirrored the moral judgments of larger society. As Alan Petersen and Deborah Lupton argue, by designating gay men early on as the main risk group for HIV/AIDS, all gay men, regardless of their sexual practices, were placed in a category that reinforced and exacerbated the social vulnerability and discrimination that they already experienced; thus, they were framed as threats to the health of the general (low-risk) population.<sup>36</sup> Hence, their pathology was not only HIV infection, but also the (non-heterosexual) sexual identities that seemed to constitute the epidemic. Within this context, as Catherine Waldby contends, HIV tests arose as a confessional technology, which, via epidemiological surveillance, would reveal the truth of one's infection and how it was transmitted. Regarding the HIV antibody test, she concludes:

The logic of the HIV test, and perhaps the biomedical representation of AIDS more generally, could be summarized as an homology: *the virus stands to the body, as the body stands to the body politic*. Just as the invisible virus is a silent danger to the immune system and the person who does not know they are [sic] infected, so too is the invisible HIV seropositive person a danger to the body politic. On the other hand the person who has been diagnosed as seropositive must take on their [sic] new identity *as virus* in a way which does not endanger the health of the body politic. They must identify themselves as virus to others.<sup>37</sup>

Self-tests for HIV still carry the same moral imperative of confession; however, as this analysis will demonstrate, consumers of home diagnostics negotiate and at times transform their use. Furthermore, as Waldby notes above, these tests are not neutral assessments of biological states; they are biopolitical technologies that identify viral bodies.

<sup>37</sup> Catherine Waldby, AIDS and the Body Politic (New York, NY: Routledge, 1996), 139.

19

<sup>&</sup>lt;sup>36</sup> Alan Petersen and Deborah Lupton, *The New Public Health: Health and Self in the Age of Risk* (Thousand Oaks, CA: Sage Publications, 1997), 58.

In *Bios: Biopolitics and Philosophy*, political theorist Roberto Esposito proposes immunization as the paradigm from which to understand contemporary biopolites. The immunity paradigm describes the need for individuals to protect or exempt themselves from the demands of the community. Life and politics, therefore, are not separate domains, but "two constituent elements of a single, indivisible whole that assumes meaning from their interaction." To attain immunity in the biomedical sense, one has to be exposed to a form of the pathogen from which one will be protected; as Esposito notes, immunity "subjects the organism to a condition that simultaneously negates or reduces its power to expand." Hence, immunity requires both the preservation of life as well as its negation. This relationship brings together both the biopolitical and thanatopolitical tendencies of contemporary politics. In this way, the negative (that is, those individuals and populations that transgress societal order and norms, including those whose very bodies are threats), become positive and productive.

#### THE BIOPOLITICS OF SECURITY

Contemporary biopolitical forms of governance rely on a number of logics to normalize their differential valuation of life. In this thesis, I link the current emphasis on biosecurity in the United States to HIV prevention and risk. Risk has become central to current interventions deployed in the name of biosecurity, which has been defined by the US National Research Council as: "security against the inadvertent, inappropriate, or intentional malicious or malevolent use of potentially dangerous biological agents or biotechnology, including the development, production, stockpiling, or use of biological weapons as well as natural outbreaks of newly emergent and epidemic diseases." While the biosecuritization of HIV prevention is not the focus of this thesis, the concluding

<sup>&</sup>lt;sup>38</sup> Roberto Esposito, *Bios: Biopoltics and Philosophy* (Minneapolis, MN: University of Minnesota Press, 2008), 45.

<sup>&</sup>lt;sup>39</sup> Ibid., 46

<sup>&</sup>lt;sup>40</sup> National Research Council, *Globalization, Biosecurity, and the Future of the Life Sciences* (Washington, DC: National Academies Press, 2006), 32.

section will postulate several lines of inquiry regarding how biosecurity logics might influence HIV prevention strategies and practices of biological citizenship. As security scholars Kezia Barker, Sarah Taylor, and Andrew Dobson note, the concept of biosecurity has become ubiquitous over the past few decades for several reasons: "overlapping security concerns, new global frameworks for managing disease risk, which impact trade and exports, and the accelerating and intensifying affects of globalization." The bourgeoning field of critical security studies reflects a growing need to understand the logics behind biosecurity interventions and their social, political, and ethical implications. Bruce Braun argues that biosecurity should be seen as a biopolitical rationality, one that cannot be separated from its ethical and political dimensions. According to Braun, biosecurity expands the biopolitical to potentially include all life forms; animals, viruses, and other organisms are now seen as actively constituting the social and political domains, "directly and intimately interwoven with human life."

While the logics of biosecurity are not uniform across sites, there are several dominant perspectives that are important to my subsequent analysis of HIV prevention practices: the radical contingency of life, an orientation towards an uncertain, catastrophic future, and the imperative of resilience. As Michael Dillon observes, emergent life, in all its complexity, creativity, and transformative potentiality, has become central to the life sciences and discourses of biosecurity. Dillon notes:

Biopolitically, security is a game in which human life as emergent biological life must be promoted and secured through the regulation and fructification of its defining transactional properties and capabilities . . . It therefore follows that biopolitical security practices must somehow deliberately allow for the transformation and change – indeed cultivate the very capacity for adaptive

<sup>41</sup> Kezia Barker, Sarah L. Taylor and Andrew Dobson, "Introduction: Interrogating Bioinsecurities," in *Biosecurity: The Socio-politics of Invasive Species and Infectious Diseases*, eds. Andrew Dobson, Kezia Barker, and Sarah L. Taylor (New York, NY: Routledge, 2013), 8.

<sup>&</sup>lt;sup>42</sup> Bruce Braun, "Power over Life: Biosecurity as Biopolitics," in *Biosecurity: The Socio-politics* of *Invasive Species and Infectious Diseases*, eds. Andrew Dobson, Kezia Barker, and Sarah L. Taylor (New York, NY: Routledge, 2013), 49.

emergence – that living contingently is now said to require of all biological things. 43

Life, therefore, cannot be secured fully from exposure to risk, since it depends on that exposure to adapt and survive. In this context, risk does not simply represent dangers to be avoided; risk can also generate profit. Risk, Dillon argues, is "the commodification of exposure to contingency calculated through the generalized measure of probability" on which the "enterprising self" now wagers. Hisk constitutes, therefore, a political rationality that coincides with the imperatives of neoliberal governance; as Nikolas Rose points out, subjects of "advanced" liberal democracies are expected to be "active individuals seeking to 'enterprise themselves' to maximize their quality of life through acts of choice, according their life a meaning and value to the extent that it can be rationalized as the outcome of choices made or choices to be made. That enterprising self now embraces certain forms of risk as potential assets and must make choices by assessing an uncertain, radically contingent future.

Filippa Lentzos and Nikolas Rose astutely observe that methods to assess and act upon a radically uncertain future are not novel; what, perhaps, is different with contemporary regimes of biosecurity, however, is the *configuration* and *centrality* of such technologies that seek to render the uncertain future into the present. Ben Anderson describes the use of "catastrophe models" as one method by which the uncertain, discontinuous future is made actionable. These models are used by insurance companies and in public policy to calculate the losses that might result from potential catastrophes (e.g., natural disasters, terrorist attacks, pandemics). In the case of emerging infectious diseases, Anderson concludes, "the effects of future pandemics are made present through numbers (such as numbers of fatalities/injuries or graphs such as exceedence probability

\_

<sup>&</sup>lt;sup>43</sup> Michael Dillon, "Underwriting Security," *Security Dialogue*, 39, nos. 2-3 (April 2008): 315.

<sup>&</sup>lt;sup>45</sup> Rose, "Governing 'Advanced' Liberal Democracies," 58.

<sup>&</sup>lt;sup>46</sup> Filippa Lentzos and Nikolas Rose, "Governing Insecurity: Contingency Planning, Protection, Resilience," *Economy and Society* 38, no. 2 (May 2009): 236.

curves) and in the form of mapping (such as global pandemic's phases)."<sup>47</sup> Biosecurity measures, therefore, do no longer only respond to crises after they occur; such technologies are used to support performative actions to intervene upon the future in the present.

In Life as Surplus, Melinda Cooper outlines how the new public health and security discourses over the past several decades have turned to emergence itself as a target of intervention. The 2002 US National Security Strategy, she observes, justified the *preemptive strike* as necessary for dealing with the uncertain future and its emerging threats. Unlike precautionary measures, which attempt to forestall future events by actions in the present, preemptive interventions, she argues, assume "that the only way to survive the future is to become immersed in its conditions of emergence, to the point of actualizing it ourselves . . . it is *future invocative* rather than predictive or representative, since the future it calls forth is effectively generated de novo out of our collective apprehensiveness."<sup>48</sup> In his review of recent biosecurity interventions in the US, Andrew Lakoff demonstrates how vital systems security approaches, which aim to preserve infrastructures (e.g., telecommunications, energy sources) that are critical for a state's social and economic survival, can displace population security and salient issues such as poverty, healthcare, and housing by focusing only on responding to catastrophes. "From the vantage of vital systems security," he notes, "whose task is to prepare for potential emergencies, the ongoing living conditions of members of the population are not a salient political problem."<sup>49</sup> Therefore, the securitization of systems can come at the expense of the population. In the name of security, life is actually rendered more insecure by diverting population resources towards a technical apparatus of preparedness. Likewise,

=

<sup>&</sup>lt;sup>47</sup> Ben Anderson. "Preemption, Precaution, Preparedness: Anticipatory Action and Future Geographies." *Progress in Human Geography* 34, no. 6 (December 1, 2010): 784.

<sup>&</sup>lt;sup>48</sup> Cooper, *Life as Surplus: Biotechnology and Capitalism in the Neoliberal Era* (Seattle, WA: University of Washington Press, 2008), 90.

<sup>&</sup>lt;sup>49</sup> Andrew Lakoff, "From Population to Vital System: National Security and the Changing Object of Public Health," in *Biosecurity Interventions: Global Health and Security in Practice*, eds. Andrew Lakoff and Stephen Collier (New York: Columbia University Press, 2008), 57.

preemption, as Anderson notes, while seemingly aiming to secure life, also destroys and injures life (as in the case of preemptive war). This "collateral damage" is not seen as a mistake or failure, Anderson continues, for in the logic of preemption, ill effects are inevitable because nonaction is unthinkable. Preemptive measures do not concern themselves with such negative impacts because, as he notes, "the proliferating effects of preemption may generate something else: opportunities to be seized."50 As one might expect, these are not opportunities for those harmed by preemptive actions, for as Anderson points out, the opportunities of preemptive war in the Middle East served the interests of security firms, contractors, and investors.<sup>51</sup>

#### RESILIENT SUBJECTS

Anderson also observes that "every attempt to stop or mitigate a threat holds certain assumptions about 'the future.'"52 Preemption engenders an orientation to the future that expects the worst; catastrophe potentially awaits around every corner. Brian Massumi notes that with preemption, the future exists in the present as a "perpetual state of potential emergence(y)," in which "the only certainty is that threat will emerge where it is least expected . . . The global situation is not so much threatening as threat generating: threat-o-genic."53 Within this state of emergency, strategies of resilience have become prominent in diverse areas such as public health as a way to manage the uncertain risks of the future.

As others have argued, resilience initiatives, as techniques of governance, are congruent with the aims of neoliberalism.<sup>54</sup> The goal of contemporary resilience-building

<sup>52</sup> Ibid., 780.

<sup>&</sup>lt;sup>50</sup> Anderson, "Preemption, Precaution, Preparedness: Anticipatory Action and Future Geographies," 790.

51 Ibid.

<sup>53</sup> Brian Massumi, "Potential Politics and the Primacy of Preemption," Theory & Event 10, no. 2 (2007): paragraphs 23-24, accessed July 4, 2015, http://muse.jhu.edu/journals/theory and event/v010/10.2massumi.html.

<sup>&</sup>lt;sup>54</sup> For example, see Brad Evans and Julian Reid, Resilient Life: The Art of Living Dangerously (Cambridge, UK: Polity Press, 2014); Jeremy Walker and Melinda Cooper, "Genealogies of Resilience:

interventions is not to prevent such threats, nor simply to prepare for their occurrence, but instead to transform populations. As Lentzos and Rose describe it: "a logic of resilience would aspire to create a subjective and systematic state to enable each and all to live freely and with confidence in a world of potential risks.<sup>55</sup> Resilience, therefore, does not seek to avoid these shocks or disturbances (whether they be socially- or ecologicallygenerated) nor does it seek simply to bounce back from them; as Pat O'Malley observes, recent resilience-building literature promotes "embracing risk" as an opportunity to thrive and grow while reframing elements of resilience as "coping strategies" or "skills" that can be learned by anyone via proper training.<sup>56</sup>

The logic of resilience presupposes the vulnerability of its subjects.<sup>57</sup> It is no wonder then, that the populations most often targeted for strategies of resilience are those who have also suffered most from histories of structural violence and inequities. Evans and Reid argue that contemporary resilience strategies undermine a population's political capabilities and potential for meaningful resistance, responsibilizing them with adaptive "skills." A resilient subject, they conclude, "must disavow any belief in the possibility to secure itself and accept, instead, an understanding of life as a permanent process of continual adaptation to threats and dangers which are said to be outside its control. As such, the resilient subject is a subject who must permanently struggle to accommodate itself to the world, and not a subject which can conceive of changing the world, its structure and conditions of possibility."58 Producing resilient subjects makes them responsible for the outcome of their lives in the face of adversities, regardless of their source. However, in conjunction with responsibilization, becoming resilient seems to

From Systems Ecology to the Political Economy of Crisis Adaptation," Security Dialogue, 42 no. 2 (April 2011): 143-160; and Jonathan Joseph, "Resilience as Embedded Neoliberalism: A Governmentality Approach," *Resilience: International Policies, Practices and Discourses*, 1, no. 1 (2013): 38-52, Lentzos and Rose, "Governing Insecurity," 243.

<sup>&</sup>lt;sup>56</sup> Pat O'Malley, "Resilient Subjects: Uncertainty, Warfare and Liberalism, *Economy and Society*, 39, no. 4 (November 2010): 489.

<sup>&</sup>lt;sup>57</sup> Brad Evans and Julian Reid, "Dangerously Exposed: The Life and Death of the Resilient Subject," *Resilience* 1, no. 2 (2013): <sup>58</sup> Ibid., 85.

offer the potential for enhancement–for some, it is not only a matter of "bouncing back" from adversity, but instead "bouncing forward." As I will explore further in this thesis, discourses of resilience have also emerged in the field of public health, which, in certain arenas like HIV/AIDS prevention, aims to not only make socially resilient subjects, but also offers technologies to make their bodies biologically resilient. Thus, within this logic, life is secured, but, as the final section of this thesis argues, with substantial cost to the political potential of these populations.

#### METHODOLOGY AND PROJECT OUTLINE

The main analytic approach of this thesis is Foucauldian discourse analysis, which is particularly well-suited for this project because it questions accepted truths and knowledges and forces researchers to unearth their situated histories, asking, in turn, how the world these truths have produced could be different.<sup>60</sup> For Foucault, as Karen Barad notes, discourse did not refer only to language:

Discourse is not what is said; it is that which constrains and enables what can be said . . . discursive practices are the local sociohistorical material conditions that enable and constrain disciplinary knowledge practices such as speaking, writing, thinking, calculating, measuring, filtering, and concentrating. Discursive practices produce, rather than merely describe, the "subjects" and "objects" of knowledge practices.<sup>61</sup>

My analysis takes public health, regulatory, and marketing practices and communications to be discursive practices that constitute subjects and further operations of power in society. The "text" that I analyzed for this current project includes test kit packaging, marketing materials, news articles, US Food and Drug Administration (FDA) transcripts and guidance, websites, and academic research reports. As an interpretive approach to

26

<sup>&</sup>lt;sup>59</sup> Alison Howell, "Resilience as Enhancement: Governmentality and Political Economy beyond 'Responsibilisation," *Politics* 35, no. 1 (2015): 67–71.

<sup>&</sup>lt;sup>60</sup> Julianne Cheek, "Foucauldian Discourse Analysis," in *The SAGE Encyclopedia of Qualitative Research Methods*, vol. I, ed. Lisa M. Given (Thousand Oaks, CA: SAGE Publications, 2008), 355.

<sup>&</sup>lt;sup>61</sup> Karen Barad, "Posthumanist Performativity: Toward an Understanding of How Matter Comes to Matter," *Signs: Journal of Women in Culture and Society* 28, no. 3 (Spring 2003): 819.

qualitative research, Foucauldian discourse analysis does not take texts on their own terms; instead, it situates them in social/historical context and looks to read between the lines to understand how the meanings presented in these texts are constructed by discourse and productive of relations of power.

This thesis will begin by focusing on OraQuick, a rapid self-test kit for HIV that was approved by the FDA in 2012. My work facilitates an opening in the discussion regarding the social implications of home diagnostics. Sociological in nature, this project aims to illuminate the relations of power that were inherent in OraQuick's arrival to the US market, as well as to point out its potential impact on individual behavior and societal norms, particularly within intimate (sexual) relationships. Because of the dual, sometimes conflicting goals of such technologies (by which I mean, first, the profit-driven goals of the biotech and pharmaceutical industry and, second, the goal of improving public health), I argue that critical analyses such as this current project must attend to both their intended and unintended effects, which may exacerbate the social and material vulnerabilities of populations through their pathologization.

To conclude this thesis, I will offer a preliminary critique of another recent HIV/AIDS prevention technology, that is, the use of antiretroviral drugs as pre-exposure prophylaxis (PrEP). In particular, I argue that pre-exposure prophylaxis for HIV (PrEP) is congruent with the logics of biosecurity that now dominate neoliberal forms of governance. In promoting resilience and addressing vulnerability to HIV infection via a pharmaceutical intervention, the promotion of PrEP may obscure the structural and historical conditions that contribute to the higher incidence of HIV among certain populations.

#### CHAPTER 1: HOME RAPID HIV TESTING AND PRACTICES OF CITIZENSHIP

On July 3, 2012, the US FDA, the government agency that regulates drugs and medical devices, announced its first approval of a rapid home HIV test, OraQuick by OraSure Technologies. This test, the first self-test for an infectious disease approved by the FDA, is equivalent to rapid HIV tests used in medical settings since 2004. It requires a mouth swab and displays results in twenty to forty minutes. Said to be as easy to use as a home pregnancy test and heralded as a "positive step forward" in controlling the HIV/AIDS epidemic, the test arrived on pharmacy shelves in the United States in October 2012.<sup>62</sup> The FDA approval of this test is a significant development, since for over twenty years the process of testing and returning HIV results in the United States has remained under the jurisdiction of health care professionals and other authorized counselors. An undoubtedly empowering technology given its ready access and immediate results, the home rapid HIV test is a significant triumph for consumers, who can now test themselves for HIV in the privacy of their own homes and make decisions based on their status. In addition, it has great potential for improving health outcomes via early detection and treatment.

Home diagnostics symbolize much more than an extension of consumer autonomy, however. Via a discursive analysis of literature and rhetoric surrounding the home rapid HIV test, as well as a comparative analysis of a variety of other self-surveillance and self-quantification diagnostic tools, this chapter identifies several contested spaces and discourses that emerge with this technology. While home HIV testing appears to represent a demedicalization of HIV testing, it also reinforces medical

<sup>&</sup>lt;sup>62</sup> Donald McNeil Jr., "OraQuick At-Home H.I.V. Test Wins F.D.A. Approval," *New York Times*, July 3, 2012, accessed July 4, 2015, http://www.nytimes.com/2012/07/04/health/oraquick-at-home-hiv-test-wins-fda-approval.html.

authority in the private domain while constituting new practices of biocitizenship. In addition, home HIV testing is part of a growing trend to expand the reach of biomedicine via identification of the population that now poses the most risk-those who are unaware of their status. While the market is presumed to be democratic insofar as it is open to all, a closer analysis of the HIV self-test reveals that underneath its democratic impulse lies the potential to reinforce social stratification due to access. The test also contributes to the growing trend of self-surveillance that is expected from neoliberal subjects. However, the HIV self-test is not the first home diagnostic, nor is it the first time that individuals can receive their HIV test results anonymously at home. The home rapid HIV test represents the vanguard of a new form of self-diagnosis and monitoring—one that directly implicates not only the status of the tested, but also their partners. Hence, while other self-testing and monitoring devices have been framed within the context of consumer choice and empowerment, the self-test for HIV is also framed as a moral obligation, as a tool for not only monitoring one's body, but also for managing risk within intimate relationships and for society as whole. Because of the relatively recent advent of this home test, empirical and ethnographic data regarding the actual prevalence of its use and impact on public health are limited. However, my aim is to analyze the relations of power that led to the emergence of this test and to draw out some potential implications for the government of individual bodies and of society. Hence, the question is not whether these tests are empowering, but instead what kinds of power they produce and support.

This analysis is limited to the potential use of the test in the United States. The case of the United States is important in considering how the uptake of these tests may occur elsewhere, since the US approval has the potential to influence a new wave of home testing in other countries. Nevertheless, practices of biological citizenship are not homogeneous globalized phenomena; their performance is highly dependent on local context and power dynamics. Even within the same locality, specific practices are widely

variable, due to stratification, consumer choice, regulatory restrictions, and other factors. Shortly after the announcement of FDA approval, advocates in the United Kingdom, South Africa, Canada, and Australia vocalized support for the approval of rapid home testing kits in their own countries; however, it unclear precisely what impact home testing will have internationally.<sup>63</sup> A 2013 review of studies on supervised and unsupervised (home) testing concluded that the evidence is not clear that unsupervised rapid testing has high acceptability uniformly across the globe, especially in low-resource contexts.<sup>64</sup> The authors also expressed concern that studies did not demonstrate whether such tests are successful in linking individuals to care in these settings. Kenya was the first African country to develop guidelines regarding the sale of self-testing kits for HIV and at least one feasibility study has implemented a program whereby health workers can self-test themselves and partners.<sup>65</sup> The first International Symposium on Self-Testing for HIV held in April 2013 brought together experts from fourteen different nations to discuss the issues surrounding home rapid tests. While there was general consensus that home selftesting should be encouraged and supported internationally, it was also recommended that before devoting resources to its scale-up, individual countries should consider whether there is a "better, risk-free way" to achieve the same benefits, and that in lower-resource settings, it may be more valuable to focus resources on improving current programs

<sup>63</sup> For example, see Joint United Nations Programme on HIV and AIDS (UNAIDS), "An HIV Test in the Privacy of Your Own Home," July 4, 2012, accessed July 4, 2015, http://www.unaids.org/en/resources/presscentre/ featurestories/ 2012/july/20120704hometesting/; Ewa Kretowicz, "HIV Groups Want Home Testing Kit in Australia," *The Sydney Morning Herald*, July 8, 2012, accessed July 4, 2015, http://www.smh.com.au/national/health/hiv-groups-want-home-testing-kit-in-australia-20120707-21nqr.html; and Kenyon Wallace, "Health Canada Mum on Future Availability of In-home Oral HIV Test," *Toronto Star*, July 4, 2012, accessed July 4, 2015, http://www.thestar.com/news/canada/2012/07/04/health\_canada\_mum\_on\_future\_availability\_of\_inhome\_oral\_hiv\_test.html.

<sup>&</sup>lt;sup>64</sup> Nitika Pant Pai, Jigyasa Sharma, Sushmita Shivkumar, Sabrina Pillay, Caroline Vadnais, Lawrence Joseph, Keertan Dheda, and Rosanna W. Peeling. "Supervised and Unsupervised Self-Testing for HIV in High- and Low-Risk Populations: A Systematic Review," *PLoS Medicine* 10, no. 4 (April 2013), accessed May 16, 2015, http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1001414.

<sup>&</sup>lt;sup>65</sup> Sue Napierala Mavedzenge, Rachel Baggaley, and Elizabeth L. Corbett, "A Review of Self-Testing for HIV: Research and Policy Priorities in a New Era of HIV Prevention," *Clinical Infectious Diseases: An Official Publication of the Infectious Diseases Society of America* 57, no. 1 (July 2013): 126–138.

rather than this new testing method.<sup>66</sup> Hence, what we may see is an international stratification of access to home rapid tests depending on the individual assessment of each nation.

#### HOME HIV TESTS AND THE CONSTRUCTION OF BIOLOGICAL CITIZENS

Home HIV tests in the United States were first proposed to the FDA in 1986. While the rapid test had not yet been developed, one entrepreneur believed that a home collection kit was technically feasible; hence he met with the FDA to discuss the possibility of approval.<sup>67</sup> The FDA responded two years later by issuing guidance/criteria for acceptance of applications for HIV tests, requiring that 1) kits must be marketed "for professional use only within a health care environment," 2) samples must be collected by a person authorized by state or local authorities, and 3) all test results must be "reported directly to a professional health care provider for reporting and interpretation of the result to person requesting the test, as well as counseling for the individual."68 In effect, the criteria prohibited any home testing. In 1989, forced by a lawsuit by the same entrepreneur who first proposed home testing, the FDA held the first public hearings to consider home HIV tests. Public response was overwhelmingly against home testing: several members of the US Congress, the Centers for Disease Control, the American Medical Association, and even gay, lesbian, bisexual, and transgender (GLBT) activists strongly opposed it over concerns about accuracy and potential suicides as a result of learning HIV positivity on one's own. To highlight the latter concern, AIDS activists

<sup>&</sup>lt;sup>66</sup> World Health Organization (WHO), "Report on the First International Symposium on Selftesting for HIV: The Legal, Ethical, Gender, Human Rights and Public Health Implications of Self-testing Scale-up" (Geneva, CH: World Health Organization, 2013), accessed May 16, 2015, <a href="http://who.int/hiv/pub/vct/self-test/en/index.html">http://who.int/hiv/pub/vct/self-test/en/index.html</a>.

<sup>&</sup>lt;sup>67</sup> Food and Drug Administration Blood Products Advisory Committee, "Testimony of Elliot J. Millenson," March 10, 2006, accessed July 4, 2015, http://www.fda.gov/ohrms/dockets/ac/06/slides/2006-4206OPH2\_2b.pdf.

<sup>&</sup>lt;sup>68</sup> "Blood Collection Kits Labeled for Human Immunodeficiency Virus Type 1 (HIV-1) Antibody Testing; Home Test Kits Designed to Detect HIV-1 Antibody; Open Meeting," *Federal Register* 50 (February 17, 1989): 7279.

disseminated copies of an obituary of a man who committed suicide by jumping off the Golden Gate Bridge in San Francisco after learning he had HIV.<sup>69</sup> The general consensus was that citizens were not equipped to test or receive results on their own, given the intense stigma and relatively limited advancement in treatment and outcomes.

In the over two decades since then, the landscape of HIV testing and treatment in the United States has changed considerably. In 1996, the FDA reversed its stance and approved an over-the-counter home collection kit, whereby users would collect a blood sample, send it to a lab for analysis, and receive results and counseling over the phone, with appropriate referrals for positive results. 70 In 2005, a coalition including many of the same interest groups that lobbied against home testing in 1989 (physicians, GLBT activists, public health officials, and manufacturer representatives) joined to testify before the FDA Blood Products Advisory Committee in support of rapid home tests.<sup>71</sup> This meeting was convened only after OraSure announced its intent to seek FDA approval for an over-the-counter version of its rapid test. In addition, OraSure reportedly selected and paid advocates of home HIV testing to speak at the 2005 meeting, therefore supporting approval of its product.<sup>72</sup> In the seven years following, OraSure Technologies worked with the FDA to conduct required clinical trials and adapt product design to obtain approval for their product. The result, OraQuick, is currently the only rapid home test for HIV approved by the FDA. MedMira, a company that manufactures a rapid HIV test using whole blood, also participated in the 2005 advisory talks, but has yet to receive FDA clearance for a home version.<sup>73</sup>

<sup>&</sup>lt;sup>69</sup> Alexi A. Wright and Ingrid T. Katz, "Home Testing for HIV," *New England Journal of Medicine* 354, no. 5 (February 6, 2006): 438.

<sup>&</sup>lt;sup>70</sup> Melissa Whellams. "The Approval of Over-the-counter HIV Tests: Playing Fair When Making the Rules," *Journal of Business Ethics* 77, no. 1 (January 2008): 6.

<sup>&</sup>lt;sup>71</sup> Wright, and Katz, "Home Testing for HIV," 437.

<sup>&</sup>lt;sup>72</sup> Whellams, "The Approval of Over-the-counter HIV Tests," 12.

<sup>&</sup>lt;sup>73</sup> Ibid., 6.

As a point of comparison, the home pregnancy test was the first rapid home diagnostic approved by the FDA. Sarah Leavitt, in her work as a historian at the US National Institutes for Health, linked the development and FDA approval of the home pregnancy test in the late 1970s to the women's health movement. While many doctors and health officials dismissed the need for home pregnancy tests in the 1960s and early 1970s, Leavitt explains: "women found ways around these strictures and increasingly demanded access to private, personal, informed, and non-judgmental health care, of which the pregnancy test was a part."<sup>74</sup> Once abortion was made legal across the nation in 1973, women's health organizations made arrangements to expand access to pregnancy testing outside of the doctor's office and to make it more affordable. For example, members of the Chicago Women's Liberation Union conducted pregnancy testing at various locations in the early 1970s outside of the clinical setting. The tests were fairly simple to conduct, and, as one member noted, they "succeeded in demystifying medicine (at least for women who were active in the pregnancy testing project)."<sup>75</sup> Thus, when Warner-Chilcot submitted its application for the "e.p.t." (Early Pregnancy Test) to the FDA in 1976, it was meeting a demand that was clearly evident. It was approved quickly, and heralded as a "breakthrough in home diagnostics" and "a private little revolution."<sup>76</sup>

What are we to make of the differences between how these two tests emerged?

One (the pregnancy test) appears to have been part of a citizen-driven movement, while corporations seem to have played a larger role in bringing the HIV self-test to market. In fact, in a critical assessment of corporate involvement in establishing FDA guidelines for rapid home HIV tests, Melissa Whellams notes that evidence of consumer demand was

<sup>74</sup> Sarah Leavitt, "A Private Little Revolution': The Home Pregnancy Test in American Culture." *Bulletin of the History of Medicine* 80, no. 2 (Summer 2006): 327.

<sup>&</sup>lt;sup>75</sup> Wendy Kline, *Bodies of Knowledge: Sexuality, Reproduction, and Women's Health in the Second Wave* (Chicago, IL: University of Chicago Press, 2010), 79.

<sup>&</sup>lt;sup>76</sup> Leavitt, "A Private Little Revolution," 325.

not a factor in deliberations. She argues that while proponents of rapid home HIV tests claimed that they were responding to consumer desire, it would appear that there was minimal demand for the product, at least at the time of her analysis.<sup>77</sup> It is true that the dramatic shift in support for home HIV testing since the 1980s stems in part from advancement in treatments and the framing of HIV as a "chronic" disease, as well as the public health push for the routinization of testing as I discuss below. However, this turn, in comparison with the pregnancy test, also demonstrates the proliferation of alliances between private (for-profit) entities and public interest groups (e.g., non-profit entities, government agencies, universities, community activist groups, etc.). Globally, private and public entities have converged in partnerships that seek medical innovations and new markets for these products. This has been tied to the growing influence of neoliberal thought since the early 1980s, which advocated for a greater role of private industries in what had traditionally been considered "public" goods. In this "modified" market, assemblages of industry, non-profits, and other "public" entities have been forged and strengthened.<sup>78</sup> Clarke and colleagues discuss the ways that drug and device legitimization has transformed in the United States via new connections between the FDA, biotech/pharmaceutical companies, and academic establishments that "create new structural and infrastructure ties between what were formerly known as the 'public' and the 'private.'" Hence, it may no longer be possible to distinguish between private and public interests, particularly in the realm of medical devices and drugs. Likewise, it is difficult, at times, impossible, to distinguish public health discourse about HIV from corporate marketing efforts. What are the implications of these new assemblages that now bring self-diagnostics to market? What contested spaces do they open up and what does this mean for the role of corporations in generating desire for new conduct and

-

<sup>&</sup>lt;sup>77</sup> Whellams, "The Approval of Over-the-counter HIV Tests," 9.

<sup>&</sup>lt;sup>78</sup> Ken Buse and Gill Walt, "Global Public-private Partnerships: Part I—A New Development in Health?" *Bulletin of the World Health Organization*, 78, no. 4 (2000): 549.

<sup>&</sup>lt;sup>79</sup> Clarke et al., "Biomedicalization: Technoscientific Transformations," 77.

practices of biocitizenship? How are "private" interests implicated in the moral and ethical landscape that biocitizens negotiate? While the answers to these questions are open to debate, the case of the home rapid HIV test can illuminate potential scenarios.

Testimony before the FDA Blood Products Advisory Committee (BPAC) in 2012 prior to the final recommendation of approval of the OraQuick test is illustrative of the blurring of the private and public. During the open "public" hearing section of the meeting, designed to give the public a voice in FDA decisions, individuals from organizations that ranged from HIV/AIDS advocacy groups to medical associations, state public health departments, academic institutions, and religious groups voiced overwhelming support for the approval of the test. Of the twenty-four people who spoke, thirteen disclosed some sort of relationship with OraSure, ranging from payment of travel costs to fiscal sponsorship, research partnerships, and educational grants. Furthermore, the testimony consistently highlighted another important shift in ideology related to neoliberal thought: the importance of choice and option in HIV testing. In fact, in addition to framing the home test as offering more choice and control to consumers, one representative from an AIDS activist group noted: "We are morally obligated—morally obligated—to bring these tests to market and stop the spread of HIV."80 This moral obligation is two-fold. First, consumer choice and autonomy are framed as universally "good," while limiting choice as undesirable, if not unethical. Some have suggested that the FDA would have been viewed as paternalistic and as denying choice or freedom if it did not approve the test based on concerns about user competence.<sup>81</sup> The idea here is that expanding testing options will increase the number of people who are aware of their status, but this strengthening of consumer choice is also in line with neoliberal ideology

<sup>&</sup>lt;sup>80</sup> Food and Drug Administration (FDA). "Transcript of 102<sup>nd</sup> Meeting of the Blood Products Advisory Committee," May 15, 2012, accessed July 4, 2015, 207, http://www.fda.gov/downloads/AdvisoryCommittees/CommitteesMeetingMaterials/BloodVaccinesandOtherBiologics/BloodProductsAdvisoryCommittee/UCM309516.pdf. Italics mine.

<sup>81</sup> Whellams, "The Approval of Over-the-counter HIV Tests," 9.

that aims to open markets and promote private profits. Second, as I will discuss further below, the moral and social responsibility of testing implicates biocitizens who are expected to self-monitor in order to improve their own health and to minimize the risk posed to others. Nevertheless, the expansion of testing options is also inexorably linked to the relationship of biocitizens to medical authority.

#### SYMBOLIC DEMEDICALIZATION

Despite the very different implications of HIV testing and pregnancy testing, (i.e., an infectious disease vs. pregnancy, a non-pathological condition), it is remarkable how similar these home tests have been framed in press releases from the manufacturer and in the media. Referencing the "breakthrough" of HIV home rapid testing, the CEO of OraSure noted: "for the first time ever individuals will be able to use the same test that healthcare professionals have used and trusted for years and this will empower them to learn their HIV status in the comfort and privacy of their own home." This framing, of course, is not unique to pregnancy tests or home HIV tests; the supposition underlying self-diagnostic tests in general, evident from their marketing materials, is that they help consumers to become more self-directed and active in evaluating and managing their health. For example, direct-to-consumer genetic tests have also been framed as part of a "consumer empowerment movement" and as "democratizing" self-knowledge. 85

If we take seriously Foucault's claim that power is productive and generative, and that when "faced with a relationship of power, a whole field of responses, reactions,

<sup>&</sup>lt;sup>82</sup> Susan McGregor, "Neoliberalism and Health Care." *International Journal of Consumer Studies*, 25, no. 2 (June 2001): 81.

<sup>83 &</sup>quot;OraSure Technologies' CEO Presents OraQuick In-Home HIV Test (Transcript)," *Seeking Alpha*, October 10, 2012, accessed July 4, 2015, http://seekingalpha.com/article/917691-orasure-technologies-ceo-presents-oraquick-in-home-hiv-test-transcript?source=nasdaq.

<sup>&</sup>lt;sup>84</sup> Greaney, Anna-Marie, Dónal P O'Mathúna, and P Anne Scott. "Patient Autonomy and Choice in Healthcare: Self-testing Devices as a Case in Point." *Medicine, Health Care, and Philosophy* 15, no. 4 (November 2012): 383, doi:10.1007/s11019-011-9356-6.

<sup>&</sup>lt;sup>85</sup> Heidi Carmen Howard and Pascal Borry, "Is There a Doctor in the House? : The Presence of Physicians in the Direct-to-Consumer Genetic Testing Context," *Journal of Community Genetics* 3, no. 2 (April 2012): 107.

results, and possible inventions may open up," then it becomes clear how these tests can indeed be empowering. Self-diagnostics produce new forms of subjectivity, corporeal realities, and practices of biocitizenship. While all of these tests have the potential to allow people more insight into their bodies outside of the medical setting, as Barbara Cruikshank notes: "the will to empower is *neither* clearly liberatory *nor* clearly repressive; rather, it is typical of the liberal arts of conduct and the political rationality of the welfare state." In other words, empowerment is a form of radically conditioned agency that can be enabling and/or transformative, while at the same time shaped by discourse and medical authority.

Therefore, a contested space has evolved with the emergence of home and direct to consumer diagnostics: while some view their emergence as relocating individuals and tests outside of medical control (i.e., demedicalization) others have argued that such tests reinforce medicalization. Biological citizens are progressively conferred options, in a sense, rights, regarding how they will go about optimizing their health. However, we cannot speak of rights within the context of neoliberal biocitizenship without recognizing that these rights come deeply entangled with obligations to one's own body and to society. Rapid HIV testing in the privacy of one's home represents a new option or right of the biological citizen, in light of the previous restriction to the clinical or counseling domain. Though home blood collection kits, available since 1996, provide anonymous home testing, the samples are still analyzed in an approved lab, and the results are returned by phone, with counseling automatically provided to those who test positive. Now, those who purchase home kits are conferred the option to collect and test their own samples, effectively assuming the role of clinicians and public health workers.

<sup>&</sup>lt;sup>86</sup> Foucault, "The Subject and Power," 789.

<sup>&</sup>lt;sup>87</sup> Barbara Cruikshank, *The Will to Empower: Democratic Citizens and Other Subjects* (Cornell, NY: Cornell University Press, 1999), 72.

The evolution of biological citizenship also involves a gradual extension of rights and obligations whereby processes traditionally seen as part of medical control and authority are moved outside of that domain. The growth of home diagnostics represents one method of moving these processes outside of that realm, since a physician or personnel designated for that role (e.g., public health worker) was previously required to conduct these tests. In the US, this phenomenon occurs within the FDA and state regulatory framework, which often relies on expert panels. An alternative method involves defining (or redefining) such tests as nonmedical, for example, in the case of direct-to-consumer genetic tests. In 2008, when responding to cease and desist letters from the California and New York public health departments, several companies claimed that their genetic tests were not medical tests, but "personal genetic services," and as such, able to operate without direct involvement of physicians. 88 In fact, the consent form for the 23andMe Personal Genome Service clearly states that the analysis "is not a test or kit designed to diagnose disease or medical conditions, and it is not intended to be medical advice."89 Thus, one might claim that these movements represent demedicalization. However, Clark and colleagues argue that the shift from medicalization to biomedicalization actually expands the domain of medicine, from "enhanced control over external nature" to "harnessing and transformation of internal nature (i.e., biological process of human and nonhuman life forms)."90

As Peter Conrad argues, "demedicalization is usually only achieved after some type of organized movement that challenges medical definitions and control." While this may be true in the case of direct-to-consumer genetic tests that are defined as "informational" (while still providing health-related data), the case of home diagnostic

<sup>88</sup> Andrew Pollack, "Gene Testing Questioned by Regulators," *The New York Times*, June 26, 2008, accessed May 16, 2015, http://www.nytimes.com/2008/06/26/business/26gene.html.

38

\_

<sup>&</sup>lt;sup>89</sup> "Consent and Legal Agreement," *23andMe*, accessed April 5, 2015, https://www.23andme.com/about/consent/?version=1.3.

<sup>&</sup>lt;sup>90</sup> Clarke et al., "Biomedicalization: Technoscientific Transformations," 52.

<sup>&</sup>lt;sup>91</sup> Conrad, "Medicalization and Social Control," 226.

tests does not necessarily entail a full demedicalization of testing processes. If the home pregnancy test has taught corporations anything, it is that consumers will pay for a technology that empowers them to enter medical care earlier. In her study of the medicalization of reproduction, Andrea Tone argues that instead of reversing medicalization, the home pregnancy test led users to seek medical intervention, either as an abortion, prenatal care, or, in the case of some negative results, assisted reproduction technologies. Sarah Leavitt's analysis arrives at a similar conclusion:

The pregnancy test does not reduce their reliance on doctors, and prenatal care in the late twentieth century involved more and more testing and more incursions of technology. The pregnancy test is the first step: each positive result will lead to the woman's interaction in some manner with the health-care establishment, whether doctors, midwives, nurses, or other professionals [...] *The home pregnancy test relocates the beginning of the long relationship with doctors that a pregnancy brings*. <sup>93</sup>

In a similar way, the movement of HIV testing to the privacy of the home represents what Conrad terms "symbolic demedicalization." It is conceivable that a subject would attempt to "escape" the public health surveillance apparatus by testing at home. In fact, this was a concern raised at the initial 2005 FDA hearings. However, this is unlikely. The home rapid HIV test does not move the subject outside of medical authority or public health surveillance; positive results must be confirmed by a clinic or healthcare professional. The OraQuick packaging clearly indicates: "A positive result with this test does not mean that you are definitely infected with HIV, but rather that additional testing should be done in a medical setting." In the home HIV test, therefore, consumers are not paying for a definitive diagnosis—instead they are paying for the feeling of knowing and being empowered that self-testing provides.

<sup>92</sup> Andrea Tone, "Medicalizing Reproduction: The Pill and Home Pregnancy Tests," *Journal of Sex Research* 49 no. 4 (2012): 325.

<sup>&</sup>lt;sup>93</sup> Leavitt, "A Private Little Revolution," 330. Italics mine.

<sup>&</sup>lt;sup>94</sup> Conrad, "Medicalization and Social Control," 225.

<sup>&</sup>lt;sup>95</sup> Sheldon Campbell and Roger Klein, "Home Testing To Detect Human Immunodeficiency Virus: Boon or Bane?" *Journal of Clinical Microbiology*, 44, no. 10 (October 2006), 3473–3476.

In anticipation of the growth of home diagnostics, a 2001 article in the *FDA Consumer*, the official magazine of the FDA that ceased publication in 2007 (consumer information is now posted on the FDA website), assessed the utility of these tests. The overall tone of the article is cautionary. The article states: "Home test kits are meant to be an adjunct to doctor visits, not a replacement" and "Those who rely on home tests also miss out on pre- and post-test counseling, which offer information, support, competence, interpretation, and follow-up advice to consumers *that only a health-care professional can give*." Thus, the message is clear: like the pregnancy test, the hope is that the point of contact with the health care system and biomedical intervention will be moved to the earliest point possible after HIV infection. In theory, this will improve health outcomes for the biological citizen; however, access to this improvement may not be uniform.

#### STRATIFIED BIOMEDICALIZATION

While every biological citizen is expected to participate actively in monitoring and improving his or her body, the methods for doing this are not accessible to all.

Technoscientific developments target specific populations, by nature of their design, price, demographic fit, or other factors. Clarke and her colleagues recognize this as "stratified biomedicalization," by which they mean that "many people are completely bypassed, others impacted unevenly, and while some protest excessive biomedicalization intervention into their lives, others lack basic care." While the manufacturer of the OraQuick test aims to market to those perceived at higher risk, including gay men and minorities, a major concern is that the rapid home HIV test will exclude a large section of that population because the cost will be prohibitive. While historically the HIV/AIDS

<sup>&</sup>lt;sup>96</sup> Carol Lewis, "Home Diagnostic Tests: The Ultimate House Call?" *FDA Consumer* 35, no. 6 (November/December 2001): 20. Italics mine.

<sup>97</sup> Clarke et al., "Biomedicalization: Technoscientific Transformations," 61.

<sup>&</sup>lt;sup>98</sup> Donald McNeil Jr., "OraQuick At-Home H.I.V. Test Wins F.D.A. Approval," *The New York Times*, July 3, 2012, accessed May 16, 2015, http://www.nytimes.com/2012/07/04/health/oraquick-at-home-hiv-test-wins-fda-approval.html.

epidemic in the US has affected MSM (men who have sex with men) and other "highrisk" groups such as intravenous drug users and commercial sex workers at higher rates, recent studies have shown that it disproportionately affects economically impoverished urban populations. Geographically, the Southern United States has the highest number of people living with HIV/AIDS (40% of total cases). As Paltiel and Pollack observe, HIV testing is unique in that the people at highest risk and thus at greater need for testing may be populations that have the least resources to pay for it. They argue that the FDA should have considered price as a specific criterion for approval, perhaps requiring a subsidy or tiered pricing system to ensure that benefits are maximized, instead of focusing only on accuracy and safety. Sec. 101

Testimony presented during a 2005 FDA meeting cited a pilot study that showed \$15 was the upper price limit to purchase a rapid test in a sample of 240 patients with HIV. 102 A more recent study presented in 2012 showed that in a sample of 108 men who have sex with men, 45 percent would not pay more than \$20 for the test. 103 Upon its release, the OraQuick test was priced at approximately \$40. A 2006 editorial in *Annals of Internal Medicine* identified specific groups to which the test would appeal: the affluent, the "worried well," new couples, and persons with recent high-risk exposure. Of the latter, the authors note that concerns were voiced at an FDA meeting that the expected consumers of the test would be people "recovering from a 'wild night'" and

<sup>&</sup>lt;sup>99</sup> Paul Denning and Elizabeth DiNenno, "Communities in Crisis: Is There a Generalized HIV Epidemic in Impoverished Urban Areas of the United States?" XVIII International AIDS Conference. Vienna, July 18-23, 2010, accessed May 16, 2015, http://hivandhepatitis.com/2010\_conference/AIDS2010/docs/0723e 2010.html.

<sup>&</sup>lt;sup>100</sup> Centers for Disease Control and Prevention (CDC), "HIV and AIDS in the United States by Geographic Distribution Fact Sheet," June 2012, accessed July 4, 2015, http://www.cdc.gov/hiv/resources/factsheets/geographic.htm.

<sup>&</sup>lt;sup>101</sup> A. David Paltiel and Harold Pollack, "Price, Performance, and the FDA Approval Process: The Example of Home HIV Testing." *Medical Decision Making*, 30, no. 2 (March/April 2010), 217–223.

<sup>&</sup>lt;sup>102</sup> Wright and Katz, "Home Testing for HIV," 440.

<sup>&</sup>lt;sup>103</sup> Cassandra Willyard, "Recommendation of HIV Test Brings Diagnostic Dilemma Home," Nature Medicine 18, no. 6 (June 2012): 841.

"college binge drinkers." The chief executive of amfAR commented: "If the people who go out and pay for this test end up being sorority girls who had a one-night stand and worry if they're infected, that's not going to be a net positive." Analysis presented to the FDA Blood Products Advisory Committee in 2012 claimed that the OraQuick home test could potentially detect 45,000 new HIV cases and avert 4,000 new infections each year. 106 OraQuick tests are currently available online and in 30,000 outlets (including pharmacies, grocery stores, and Wal-Mart) throughout the US (www.oraquick.com), in theory available anywhere to anyone. A recent national TV ad for the test declared: "It's not a black thing, it's not a white thing, it's not a gay thing, it's not a straight thing. Testing for HIV is everyone's thing," while portraying decidedly middle-class consumers calmly testing at home. 107 While an analysis of the full OraQuick marketing plan is outside the scope of this article, it is worth noting that the Magic Johnson, former professional basketball star and HIV activist, has been hired as a spokesperson in an effort to target the African American community. However, if many of those deemed at risk for HIV cannot purchase this test due to limited resources, if indeed this results in stratified biomedicalization, there will be a significant disconnect between the claims that justified its approval and its actual effects in reducing the incidence of HIV/AIDS and detecting new cases. Rose summarizes the dilemma: "not all have equal citizenship in this biological age."109

\_

<sup>&</sup>lt;sup>104</sup> Rochelle Walensky and A. David Paltiel, "Rapid HIV Testing at Home: Does It Solve a Problem or Create One?" *Annals of Internal Medicine* 145, no. 6 (2006): 459-462.

<sup>&</sup>lt;sup>105</sup> Ian Duncan, "Drugstores Soon Will Sell Tests for HIV," *Star Tribune*, July 3, 2012, accessed May 16, 2015, http://www.startribune.com/lifestyle/health/161302315.html.

<sup>&</sup>lt;sup>106</sup> Willyard, "Recommendation of HIV Test Brings Diagnostic Dilemma Home," 841.

<sup>&</sup>lt;sup>107</sup> "OraQuick Television Advertisement," YouTube video, 0:43, posted by *Orasure*, December 2012, accessed July 4, 2013, http://www.youtube.com/watch?feature.player\_detailpage&v.82rV3jgg-Hk.

<sup>&</sup>lt;sup>108</sup> Jessica Cumberbatch Anderson, "Magic Johnson: OraQuick, The First At-Home HIV Test, Is 'A Game Changer," *Huffington Post*, October 15, 2012, accessed May 16, 2015,

http://www.huffingtonpost.com/2012/10/15/magic-johnson-oraquick-hiv-home-test-game-changer.

<sup>109</sup> Rose, The Politics of Life Itself, 132.

# CHAPTER 2: RISK AND THE UNTESTED BODY

As Deborah Lupton has observed, the contemporary meaning of "risk" as "danger" permeates public health discourse and serves as "an effective Foucauldian agent of surveillance and control that is difficult to challenge because of its manifest benevolent goal of maintaining standards of health." The discourse surrounding HIV is ripe with references to risk, levels of risk, and those at risk. In 2006, the US Centers for Disease Control and Prevention (CDC) revised its recommendations in an effort to routinize HIV testing. Specifically, it recommended general screening of patients in health care settings, testing of all pregnant women unless they opt-out, and most notably, removed the requirement for pre- and post-test counseling. The current guidelines state: "the effectiveness of using risk-based testing to identify HIV-infected persons has diminished."111 While this revision may appear to reduce the role of risk in HIV public health discourse, the alternative interpretation is that instead *everyone is at risk*. Petersen and Lupton observe that the new public health focus on the "environment" (as broadly defined) serves to disband the categories of "healthy" and "unhealthy" populations; instead, "everything potentially is a source of 'risk' and everyone can be seen to be 'at risk."112 A similar phenomenon has occurred with HIV. While earlier strategies focused on targeted testing of populations deemed to be high risk, contemporary efforts appear to have focused on testing the general population in order to reduce transmission by earlier treatment and identification of seropositive individuals. This expansion of the at-risk population serves both the interests of organizations charged with protecting public

<sup>&</sup>lt;sup>110</sup> Deborah Lupton, "Risk as Moral Danger," 432-433.

<sup>111</sup> Bernard M. Branson, H. Hunter Handsfield, Margaret A. Lampe, Robert S. Janssen, Allan W. Taylor, Sheryl B. Lyss, and Jill E. Clark, "Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-care Settings," *MMWR Recommendations and Reports*, 55 (September 22, 2006): 1–17.

<sup>112</sup> Lupton, "Risk as Moral Danger," 195.

health (e.g., the CDC) and companies that manufacture these tests, under the purported goal of achieving "health for all."

# HIV SELF-TESTING AND THE CONSTRUCTION OF "RISKY" BODIES

The framework of biological citizenship traditionally emphasizes the active nature of the neoliberal subject. However, as noted previously, practices of biocitizenship are not uniform. While the population in general has been identified as at risk for HIV, the most "risky" bodies now are those who have not been tested, those who have not fulfilled their duties as biological citizens in actively monitoring their status. What are we to make of these inactive citizens? These subjects comprise a specific category of biocitizens: the "untested bodies." These untested bodies are simultaneously at risk while posing a risk. By not monitoring their HIV status and abandoning the obligation to constantly assess and improve their health, the untested citizens pose a threat to the community of active, informed biological citizens who are aware of their status. Contemporary public health discourse surrounding HIV testing, including the OraQuick home test, stresses the need to identify the people in the US who have HIV and are unaware of their status. Much of the impetus and justification for the OraQuick test centered around evidence collected by the CDC which showed that approximately one in five people in the US who have HIV do not yet know it. Thus, the test would theoretically reach those who for whatever reason have not submitted to a clinical test (e.g., those who do not divulge risky practices to their doctors, with limited access to health care, or in rural areas without HIV testing centers). 113 The efforts to reach these untested bodies can be seen as an attempt to rehabilitate biological citizens, in a sense, to bring them back into the fold of the "regime of self" as actively taking responsibility for their health.<sup>114</sup> The status of the "untested body" may be transitory. One may test negative and then engage in a risky activity (e.g.,

<sup>&</sup>lt;sup>113</sup> Carrie Arnold, "At-home HIV Test Poses Dilemmas and Opportunities," *The Lancet* 380, no. 9847 (September 22, 2012): 1045–1046.

<sup>114</sup> Rose, The Politics of Life Itself, 154.

unprotected sex or needle sharing), thus returning to the status of the "untested." However, awareness of one's HIV status is simply the beginning stage of a self-maintenance regime; those who test negative are counseled to take specific steps (e.g., practice safer sex, avoiding sharing needles, etc.) to minimize their risk of contracting HIV, and those who test positive are directed by counselors and health care professionals to take steps to minimize the effects of the disease on their bodies and the chance of passing it on to others (e.g., beginning antiretroviral treatment, practicing safer sex, disclosing status to partners). 115

However, when we consider the potential for stratification of access to HIV selftests, a paradox emerges: while the discourse regarding the untested bodies emphasizes their rehabilitation via self-testing, it is probable that a large section of this class of biocitizens will find the cost prohibitive. Stratified biomedicalization, as a dividing practice, carries a moral valence and infuses all levels of society. Certain bodies and identities are seen as needing technologies by virtue of their "risky" behaviors and lifestyles. 116 Even within these "risky" groups, those who do not participate, for whatever reason, in the technologies of health, are often excluded or deemed morally deficient.<sup>117</sup> It is within this context that the involvement of corporate capitalism and its fusion with the scientific endeavor gets caught up with the shaping of citizen practices and moral systems. While the scientific endeavor may claim its goal as the objective promotion of human well-being, corporate capitalism appears to eschew a moral valence in its pursuit of profit. However, this assemblage has the potential of reinforcing a moral system that already deems the untested as irresponsible biocitizens. If indeed many of the untested cannot afford to self-test (and have not found other means of testing as feasible), then they may be further ostracized due to their seeming dereliction of

<sup>115</sup> Petersen and Lupton. The New Public Health. 70.

<sup>116</sup> Clarke et al., "Biomedicalization: Technoscientific Transformations," 83.

<sup>117</sup> Rose, The Politics of Life Itself, 25.

citizenship duties. Hence, an ostensibly democratizing technology may reinscribe social stigma on these bodies because it is priced outside of their range. The vital moral obligation to oneself and others of HIV testing makes the moral divide between the tested and untested even more concerning and is what differentiates the HIV home test from other over-the-counter diagnostics. Neither the home pregnancy test nor direct-to-consumer genetic testing can claim the same moral urgency.

#### SURVEILLANCE OF SELF AND OTHERS

Techniques for self-surveillance have proliferated in recent years, from online risk-assessment tools to more dynamic self-monitoring systems. For example, the growth of "self-quantification" as a method of health assessment has stimulated invention of a myriad of self-tracking devices and programs, as well as online communities such as the "Quantified Self," in which self-trackers discuss their experiences monitoring minute details such as weight, blood pressure, calories, heart rates, and menstrual cycles. Many of these new technologies are available without direct involvement of physicians. The active patient-consumer, therefore, has an ever-growing array of methods from which to choose to fulfill his or her duties of biological citizenship. Health and life in general, therefore, are more intensely biomedicalized via these advancements in self-monitoring, while appearing less medicalized as the responsibility shifts from the health care professional domain to the patient-consumer. 119

However, public health discourse is not only concerned with self-development and self-surveillance; protecting one's health also involves the surveillance of others.

Anti-smoking campaigns have urged citizens to not only stop smoking themselves, but to monitor others, to protect "the masses from 'other people's smoke,' for example by

46

<sup>&</sup>lt;sup>118</sup> Phillip Bethge, "Tech Pioneers Track Bodily Functions Day and Night," *Spiegel Online*, January 5, 2012, accessed May 16, 2015, http://www.spiegel.de/international/world/new-trend-towards-self-monitoring-using-high-tech-equipment-a-829454.html.

<sup>&</sup>lt;sup>119</sup> Clarke et al., "Biomedicalization: Technoscientific Transformations," 65.

insisting that others do not smoke inside one's house."<sup>120</sup> The purpose of this surveillance of others is both in self-interest and that of the community. Health monitoring of others has entered private spaces and rituals, even those considered to be "risky" domains. For example, in a European study of the effects of safe-sex promotion one interviewee who worked as a bouncer at an S/M leather club noted that staff policy was to exclude members who were observed engaging in "deviant" (i.e., unsafe) practices. The author concludes: "A socially and sexually 'deviant' group were policing themselves to ensure members did not deviate from the 'liberal' rhetoric of health promotion." However, as Annemarie Mol points out, while hegemonic health discourse may seem totalizing, "(medical) science does not have the power to impose its order on society." Instead, she argues, if it succeeds, it is because actors in society take it up (or adopt what suits their needs), forming new networks and associations.

The experience of Dan, as reported in a US news outlet shortly after the release of the HIV self-test, is illustrative of this dynamic:

Dan Nainan had never heard of a home test for HIV until a prospective girlfriend insisted that he take one. Apparently, she didn't trust him. "I'm not some sleaze bag, but she's really suspicious," said Nainan, 31, who works as a comedian. "I'm like, 'Come on, you're kidding me." The test became a sticking point in their budding relationship. "I didn't feel I had anything to be worried about," Nainan said, "but she didn't want to proceed." He finally gave in and took the test his girlfriend foisted on him, certain he'd test negative. He swabbed his gums – the test works on saliva – put the test swab in a test tube and waited as his girlfriend grilled him about his sexual history. "It was a bit uncomfortable," Nainan said. Ten tense minutes passed as he watched a deep-pink line appear slowly in a tiny window on the testing device. He prayed it wouldn't be joined by a second line signaling a positive result, and wondered what he'd do if it did emerge. "I felt like I was taking a pregnancy test," Nainan said.

120 p. (

<sup>&</sup>lt;sup>120</sup> Petersen and Lupton, *The New Public Health*, 69.

<sup>&</sup>lt;sup>121</sup> Anthony Pryce, "Frequent Observation: Sexualities, Self-surveillance, Confession and the Construction of the Active Patient," *Nursing Inquiry*, 7, no. 2(June 2000), 108.

<sup>&</sup>lt;sup>122</sup> Annmarie Mol, *The Body Multiple: Ontology in Medical Practice* (Durham, NC: Duke University Press, 2002), 63-64.

<sup>123</sup> Karin Halperin, "Home Testing for HIV—Reading the Lines in Do-It-Yourself Test," *ABC News*, December 18, 2012, accessed May 16, 2015, http://abcnews.go.com/Health/hiv-home-testing-oraquick-hits-stores-raises-questions.

Rapid over-the-counter HIV tests may also serve as a tool by which consumers can "police" others while acting in self-interest. Prior to FDA approval, some expressed concern that the tests would be used inappropriately to test others secretively without their consent or under conditions of coercion. 124 However, discourse after FDA approval indicated a different type of surveillance. Though not advertised by the manufacturer as a potential use, some have advocated using the test to screen potential partners, and stories such as the one cited above show that it is being used in this way. Seventy percent of the 4,000 participants in the clinical trials conducted before OraQuick's approval indicated that they would definitely or very likely use it in this manner. <sup>125</sup> One recent study conducted in New York City investigated the utility of partner screening with the new rapid HIV test in a population (N=27) of HIV-negative men who have sex with men (MSM) who regularly had unprotected sex with multiple partners. The expectation was that if a potential partner tested positive for HIV, subjects would refrain from unprotected sex. Subjects were each given 16 tests to use before sexual encounters and were monitored for three months. One hundred partners were tested during the course of the study, and ten tested positive (six who were previously unaware of their status). While the authors claim that "very few problems occurred," they also note that using the OraQuick test to test partners is problematic, since it may not accurately detect HIV antibodies until after the three-month window period. 126

#### SOMATIC ETHICS AND PARTNER SCREENING FOR HIV

It is not clear whether this new home diagnostic will be widely used in this way (the cost may be prohibitive), but the potential for surveillance of others represents an

124 Whellams, "The Approval of Over-the-counter HIV Tests," 8.

<sup>125</sup> Donald McNeil Jr., "Another Use for Home H.I.V. Test: Screening Partners," *New York Times*, October 5, 2012, accessed May 16, 2015, http://www.nytimes.com/2012/10/06/health/another-use-for-home-hiv-test-screening-partners.html.

<sup>126</sup> Alex Carballo-Diéguez, Timothy Frasca, Ivan Balan, Mobolaji Ibitoye, and Curtis Dolezal, "Use of a Rapid HIV Home Test Prevents HIV Exposure in a High Risk Sample of Men Who Have Sex With Men," *AIDS and Behavior* 16, no. 7 (October 2012): 1753.

evolving responsibility for biological citizens. This responsibility has shifted from monitoring not only behavior, but also the actual health status, lifestyles, bodies, and activities of other citizens in order to protect one's own health and in the name of empowerment. However, this is more than need for self-protection. Indeed, it is deeply embedded within the ethical conduct that has emerged against the backdrop of biopower and biocapital, a conduct which Rose terms "somatic ethics." HIV testing in its myriad forms, entails a particular form of ethics of personhood and the body, one that, as Rose notes: "concerns itself with the self-techniques by which human beings should judge and act upon themselves to make themselves better than they are." This ethical responsibility, therefore, requires that citizens take up practices not only individually, but also in relation to others.

Partner screening for HIV has a complex history of practice, in particular among MSM who engage in unprotected sex with multiple partners. In a New Zealand study reported in the late 1980s (Horn and Chetwynd, 1989), one participant described how he would feel under the partner's arms for swollen lymph glands to assess HIV status. <sup>129</sup> A study conducted in Montreal in the early 1990s described the process of inspection that participants employed to screen partners for HIV status, for example, by looking for Kaposi's sarcoma lesions and evaluating muscle tone for signs of wasting. <sup>130</sup> (Aveline, 1995). Partner screening with over-the-counter rapid HIV tests constitutes a similar form of knowledge production, with the credibility that technoscientific innovations provide. Yet partner testing is not simply an imposition "from above" of a new medical technology as a tool for surveillance. As noted previously, the biological citizen is not a

<sup>127</sup> Rose, The Politics of Life Itself, 257.

<sup>&</sup>lt;sup>128</sup> Ibid., 27.

<sup>&</sup>lt;sup>129</sup> Jaqueline Horn and Jane Chetwynd, "Changing Sexual Practices amongst Homosexual Men in Response to AIDS: Who Has Changed, Who Hasn't and Why?" (Report to the New Zealand Department of Health, September 1989).

<sup>&</sup>lt;sup>130</sup> David Timothy Aveline, "A Typology of Perceived HIV/AIDS Risk-reduction Strategies Used by Men Who 'Cruise' Other Men for Anonymous Sex," *Journal of Sex Research* 32, no. 3 (1995): 201–212.

passive recipient of health discourse. Clarke and colleagues argue that processes of biomedicalization are contingent on how individuals negotiate them, sometimes even transforming them to meet their needs. 131 In her study of the lesbian use of assisted reproductive technologies, Laura Mamo argues that the application of these technologies can be both controlling and creative of agency. She concludes: "Lesbian participants negotiated conception with eyes wide open. As healthcare consumers, they maneuvered through biomedical landscapes with intentionality and deliberation." Likewise, individuals who use the home HIV test to screen sexual partners are negotiating this technology by using it outside of its officially approved purpose. The OraQuick packaging clearly states that one should not use the test "to make decisions based on behavior that may put you at risk for HIV" given the possibility of a false negative. Yet, we misread partner testing if we assume that users believe that these tests are infallible. In fact, in testimony to the FDA in reference to the study on MSM described above, Dr. Carballo-Diégez noted that when subjects were asked whether they understood that the result might not be accurate given the window period, they all responded in the affirmative. However, as he testified: "They see the possibility of testing partners as something much better than doing 'ocular' virology – if I look at you and I think you look good, so probably you're not infected. They feel much more empowered when they have a test that they can use to test someone."<sup>133</sup> Hence, those who choose to test partners are negotiating the use of a medical technology to fit their own needs and circumstances to protect themselves from HIV infection and to fulfill a societal obligation. In addition, they demonstrate conviction in a medical technology to provide

-

<sup>131</sup> Clarke et al., "Biomedicalization: Technoscientific Transformations," 56.

<sup>132</sup> Laura Mamo, *Queering Reproduction: Achieving Pregnancy in the Age of Technoscience* (Durham, N.C.: Duke University Press, 2007), 156.

<sup>133</sup> FDA, "Transcript of 102<sup>nd</sup> Meeting of the Blood Products Advisory Committee (BPAC)," 148.

an objective evaluation instead of relying on visual assessments or the partner's word, despite the possibility that this calculation may not be completely accurate.

Yet, those desires and convictions are still framed within the discourse of risk and surveillance and contribute to the economic bottom-line of corporations. Drawing from Foucault on her work on the democratic citizen, Cruikshank argues that "it is to be in a tangled field of power and knowledge that both enables and constrains the possibilities of citizenship . . . citizens are made and therefore subject to power even as they become citizens."<sup>134</sup> Viewed in this way, performances of biocitizenship, while embodying norms, can also be acts of agency. These acts of biocitizenship have the potential to usher in new forms of subjectivity and ways of becoming intimate. These are biocitizens who, via this performative act, may no longer simply view the body as a potential object of examination by medical authority, but as something to be self-tested at the deepest molecular level. For some, this is part of a life-long process of such examination, as the methods by which biocitizens are able test themselves and others proliferate. It is from these complex networks of health discourse, corporate marketing, and individual material needs that such practices emerge. For example, as of 2012, one US company (www.status-negative.com) instituted a subscription service whereby HIV test collection kits are sent quarterly, with negative results posted on a private member page. A code is given that can be shared with others who can look them up and verify test results. The website encourages consumers to "join the ranks of the empowered and responsible dating Americans" and to share their member pages with partners (and to "make sure they show you theirs"). In a similar way, the home rapid HIV test may become a "gatekeeper" for partners and relationships, as in Dan's case described above. Partner testing has potential implications for the configurations of sexual relationships and

<sup>134</sup> Cruikshank, The Will to Empower, 20.

practices as biocitizens learn of others' status in the home and make immediate decisions based on that result.

# CONCLUSION: CHEMOPROPHYLAXIS FOR HIV AND THE RESILIENT BODY

The FDA Antiretroviral Advisory Committee held a public meeting in May 2012 to discuss whether to recommend approval of a combination of antiretroviral drugs (tenofovir/emtricitabine, trademark Truvada by Gilead Sciences) for pre-exposure prophylaxis (PrEP) for HIV. As indicated by its designation (pre-exposure prophylaxis), the once-daily drug is intended to be taken by those who do not have HIV before they may be exposed to the virus; if a person on the regimen is exposed to HIV, Truvada intervenes in the infection process by preventing the replication of the virus. 135 At the end of the meeting, the advisory committee recommended approval of the drug as prophylaxis to reduce the risk of sexually acquired infections in high-risk populations. In July 2012, the same month in which it issued approval for the OraQuick HIV test, the FDA issued final approval of Truvada for this new indication.<sup>136</sup> While these two technologies differ substantially in their biological mechanisms (one being a diagnostic test and the other a pharmaceutical intervention), they both constitute efforts to produce biological citizens who take responsibility for their health despite their vulnerability to HIV. In the final part of this thesis, I offer a critique of HIV chemoprophylaxis and the logics that make such biomedical interventions possible. My discussion will focus on two critical areas: 1) PrEP as a practice of biological citizenship and intensification of biomedicalization and 2) PrEP's congruence with logics of security and resilience.

#### PREP AND THE CONSTRUCTION OF BIOLOGICAL CITIZENS

Like the home HIV test, PrEP is one way via which biological citizens are made in society; however, unlike the self-test, it is not intended for a general population. In the

<sup>135</sup> Gilead Sciences, "About Truvada for PrEP Indication," June 2014, accessed July 6, 2015, http://www.truvadapreprems.com/pre-exposure-prophylaxis.

<sup>&</sup>lt;sup>136</sup> David Holmes, "The US Treads Carefully with PrEP," *Lancet* 12, no. 7 (July 2012): 515-516.

US, PrEP is indicated only for HIV-negative adults who are at "high risk" for infection. This particular aspect is key: as a prevention technology in the United States, PrEP is intended *for those who, according to public health knowledge, are most vulnerable to HIV infection*. These are populations that, for the most part, seem stubbornly unresponsive to public health efforts to reduce or eliminate behaviors that put them at risk for HIV.<sup>137</sup> However, as noted in the previous chapter, seemingly unscientific methods of risk reduction have persisted since the advent of HIV/AIDS in the United States. Like the untested bodies who are in need of the HIV self-test, PrEP offers many of those who are in the highest-risk categories for HIV a scientifically legitimated method of minimizing risk of infection despite exposure to the virus.

On one hand, the advent of PrEP seems to signal a shift away from traditional prevention techniques aimed more directly at disciplining sexual practice (e.g., condom use, serosorting, reduction of partners, etc.) towards one that seems to accept that certain individuals will continue these "risky practices" regardless of public health efforts to change them. Nevertheless, *behavioral interventions are essential to PrEP administration*, extending and normalizing medical surveillance of sexual practice and the body, as well as compliance with pharmaceutical regimens. PrEP requires a oncedaily dosage; clinical trials have shown that its efficacy in preventing HIV infections correlates strongly with adherence to the daily regimen/blood levels of the drug.<sup>138</sup>

<sup>137</sup> The CDC Guidelines state: "For sexual transmission, this includes anyone who is in an ongoing relationship with an HIV-positive partner. It also includes anyone who 1) is not in a mutually monogamous relationship with a partner who recently tested HIV-negative, and 2) is a gay or bisexual man who has had anal sex without a condom or been diagnosed with an STD in the past 6 months; or heterosexual man or woman who does not regularly use condoms during sex with partners of unknown HIV status who are at substantial risk of HIV infection (e.g., people who inject drugs or have bisexual male partners)." Centers for Disease Control and Prevention (CDC), *Preexposure Prophylaxis for the Prevention of HIV Infection in the United States—2014: A Clinical Practice Guideline* (Atlanta, GA: CDC, 2014), 21, http://www.cdc.gov/hiv/pdf/PrEPguidelines2014.pdf, accessed May 16, 2015. This current analysis will focus on its indication for individuals who are not in monogamous relationships and have used condoms inconsistently.

 <sup>138</sup> Linda J. Koenig, Cynthia Lyles, and Dawn K. Smith, "Adherence to Antiretroviral Medications for HIV Pre-Exposure Prophylaxis," *American Journal of Preventive Medicine* 44, no. 1, S91 - S98.

Therefore, in contrast to a vaccine, if an individual on PrEP acquires HIV infection, the failure can be easily attributed to the person, not the prescribing physician or the pharmaceutical itself. In order to better understand the potential social implications of this technology, more critical studies are necessary; however, my analysis for this thesis has identified several "breaking points," outlined as follows.<sup>139</sup>

While the public health support for PrEP seems to suggest that certain risky practices have become normalized (or at least are no longer the chief focus of intervention), in order to utilize PrEP fully, a subject must conform to other citizenship practices, entering other relations of power. For example, according to CDC guidance, PrEP should be administered in conjunction with:

- 1. An initial HIV risk behavioral assessment and HIV antibody test.
- 2. Test of renal function (serum creatinine test) and for hepatitis B and C.
- 3. Once prescribed, patients should return for follow-up every three months for an HIV test, assessment of side effects, adherence, and risk behaviors; every six months for renal function assessment and testing for other sexually transmitted infections (e.g., gonorrhea, syphilis, chlamydia).
- 4. Providers are also expected to provide adherence counseling and support, as well as ongoing, patient-specific counseling to reduce risk behaviors. 140

Hence, what emerges in the context of PrEP is not only a pharmaceutical regimen, but more broadly, perhaps, a system of governance that responsibilizes these subjects for their own health while they become accustomed to regular medical monitoring of their bodies and sexual risk practices. Like the home HIV test, however, those who are at highest risk for HIV, and thus, according to its indication, in need of it most, may not so easily access PrEP due to lack of health care coverage and funds. While the

\_

Butler, "What is Critique?" paragraph 35.

<sup>140</sup> Centers for Disease Control and Prevention (CDC), Preexposure Prophylaxis for the Prevention of HIV Infection in the United States—2014: A Clinical Practice Guideline, 38-46.

manufacturer has established a medical assistance program for those who do not have health insurance to cover PrEP, this does not address the broader issue: PrEP is intended to be administered through a primary care model, and many at higher risk for HIV may not engage with the health care system in this manner, if at all.<sup>141</sup> Thus, PrEP's promised impact may remain unrealized as long as such structural barriers are left unattended.

Those who are prescribed PrEP, however, are not to be passive recipients. While this technology certainly has the potential to divide society into those deserving and underserving of intervention, it also binds those who come to see themselves as potential beneficiaries of its protection. These active/activist biocitizens embody a form of biosociality, which, as Nikolas Rose argues, is "pioneering of a new informed ethics of the self—a set of techniques for managing everyday life in relation to a condition, and in relation to expert knowledge." These biocitizens are encouraged to educate their physicians about PrEP; the CDC has even provided a flyer for individuals to use when talking to their doctors, with sections that include questions to ask, directions on how to prepare for the visit, and resources to provide one's physician. In such cases, the traditional roles of the patient, physician, pharmaceutical company, and public health agency are blurred and, at times, seemingly reversed.

Pre-exposure prophylaxis for HIV also entails a shift in how biomedicine conceptualizes disease. In her discussion of the treatment of breast cancer risk with pharmaceuticals ("chemoprevention"), Jennifer Fosket notes that what makes this use uniquely biomedicalized is "the way in which it conceptualizes risk as a treatable health problem. Within the schema of chemoprevention, breast cancer risk becomes something

56

\_

 <sup>&</sup>lt;sup>141</sup> Jared M. Baeten, Jessica E. Haberer, Albert Y. Liu, and Nirupama Sista, "Preexposure Prophylaxis for HIV Prevention: Where Have We Been and Where Are We Going?" *Journal of Acquired Immune Deficiency Syndrome* 63, no. 2 (July 2013): S122–129.
 <sup>142</sup> Rose, *The Politics of Life*, 146.

<sup>&</sup>lt;sup>143</sup> Centers for Disease Control and Prevention (CDC), "Talk to Your Doctor About PrEP," accessed May 12, 2015, http://www.cdc.gov/hiv/pdf/risk PrEP TalkingtoDr.pdf.

detectable, diagnosable, and treatable with pharmaceuticals."<sup>144</sup> The way in which HIV risk is now assessed and treated via PrEP appears to enact a similar logic. Nevertheless, what distinguishes the use of antiretrovirals to prevent HIV is that their use intervenes upon a risk that historically has been attributed to individual behavior instead of the environment (e.g., pre-exposure prophylaxis for malaria) or biology (e.g., genetic markers for breast cancer). In 2014 guidance, the CDC clarified certain factors that would qualify someone as high risk for HIV (and thus indicated for PrEP), which include, among others, sex work, recent diagnosis of an STD, multiple sexual partners, and inconsistent condom use in the past six months. 145 Clinical risk assessments for HIV most often highlight such individual behaviors as factors. 146 At the societal level, the use of chemoprevention for HIV more closely binds the at-risk individuals with those who are HIV-positive, who may share similar prescriptions. This association is evident when research reports highlight the problem of stigma as a barrier to PrEP adherence and uptake; there is not only the fear that they might be mistaken as HIV-positive for taking antiretrovirals, but, among certain communities, as one report noted, "individuals may see taking PrEP as an admission that they are engaging in behaviors that put them at risk for infection."<sup>147</sup> It is possible, therefore, that for some, PrEP supports the

<sup>&</sup>lt;sup>144</sup> Laura Fosket, "Breast Cancer Risk as Disease," in *Biomedicalization: Technoscience, Health, and Illness in the U.S.*, eds. Adele E. Clarke, Jennifer Ruth Fosket, Laura Mamo, Jennifer R. Fishman, and Janet K. Shim (Durham, NC: Duke University Press, 2010), 333.

<sup>145</sup> The CDC Guidelines state: "For sexual transmission, this includes anyone who is in an ongoing relationship with an HIV-positive partner. It also includes anyone who 1) is not in a mutually monogamous relationship with a partner who recently tested HIV-negative, and 2) is a gay or bisexual man who has had anal sex without a condom or been diagnosed with an STD in the past 6 months; or heterosexual man or woman who does not regularly use condoms during sex with partners of unknown HIV status who are at substantial risk of HIV infection (e.g., people who inject drugs or have bisexual male partners)." Centers for Disease Control and Prevention (CDC), "Pre-exposure Prophylaxis (PrEP)," June 25, 2015, accessed July 4, 2015, http://www.cdc.gov/hiv/prevention/research/prep/.

<sup>146</sup> For example, the "MSM Risk Index" included in the CDC's PrEP Clinical Providers' Supplement includes only 6 questions, four of which ask about sexual practices in the last six months, and one which asks about drug use. Centers for Disease Control and Prevention (CDC), *Preexposure Prophylaxis for the Prevention of HIV Infection in the United States—2014: A Clinical Practice Guideline*, 21.

<sup>&</sup>lt;sup>147</sup> Sarit A. Golub, Don Operario, and Pamina M. Gorbach, "Pre-exposure Prophylaxis State of the Science: Empirical Analogies for Research and Implementation," *Current HIV/AIDS Reports* 7, no. 4 (November 2010), 204.

pathologization of risk behaviors, behaviors that are then inscribed in the body via the practice of taking a daily dose, follow-up appointments with the physician, and the pharmaceuticals coursing through one's blood. Nevertheless, as noted previously, the contemporary conception of risk, and particularly within security discourse, does not always entail danger. Instead, such exposure can generate profit and growth. In this context, what perhaps we are seeing is not a normalization of risky practices per se, and instead a normalization of living a "risky" life, exposed to danger, while simultaneously enterprising of the self.

#### RESILIENT SUBJECTS TO RESILIENT BODIES

In highlighting the ways in which contemporary biosecurity initiatives have the potential to transform and expand the reach of neoliberal governance, Filippa Lentzos and Nikolas Rose argue that a broader analysis of security governance would need to look more closely at how "the instrumentalization of anxiety and the objective of many of the technologies being installed that seek to intensify and utilize the subjective states of alertness, suspicion and the monitoring of the daily conduct and attitudes of others as the means of extending or appearing to extend the reach of security into the interstices of everyday existence." <sup>148</sup> I propose that a productive framework through which one could analyze the emergence of PrEP in the US is through the logics and discourses of security, which have become an integral part of neoliberal biopolitics. My analysis of PrEP as securitization has identified several points of contention, as follows.

The explicit connection between HIV/AIDS and security has been well established. Stefan Elbe has discussed extensively the implications of the securitization of HIV/AIDS, whether in the name of human security, national security, or international security. 149 To employ security frameworks to investigate a public health strategy like

Lentzos and Rose, "Governing through Insecurity," 247.
 Stefan Elbe, Virus Alert: Security, Governmentality, and the AIDS Pandemic (New. York, NY: Columbia University Press, 2009).

PrEP, is not to suggest that security discourse has colonized the field of HIV/AIDS prevention. As Elbe argues, the securitization of HIV/AIDS is not simply another case of the state utilizing medicine and public health for its political ends; it also represents a case in which medicine and public health are deploying security discourse for their own purposes. "One could even say," Elbe concludes, "that security here is effectively becoming the *continuation of medicine by other means*, because the language of security is being deliberately mobilized in order to serve a wider public health and humanitarian purpose."<sup>150</sup> An analysis of PrEP as security discourse, therefore, would not only consider how security logics have been taken up by HIV/AIDS prevention efforts, but also how their meanings are transformed as they are adopted.

While PrEP has not been explicitly framed as a security intervention in public health discourse, the language and logics of security seem to coincide with its goals in several crucial ways. For example, in late 2009, Nature Medicine reported on the massive clinical trials of pre-exposure prophylaxis that were underway at the time (over 18,000 participants in ten countries). As early as 1995, the author mentioned, antiretrovirals had been investigated for HIV prevention after exposure, but "no one seriously considered giving antiretrovirals to healthy, unexposed people" due to their cost, potential side effects, and a certain optimism among researchers that an easier, less expensive intervention (e.g., a vaccine) would be soon developed.<sup>151</sup> Despite significant barriers to implementing PrEP (cost and risks/side effects of the drugs), the researchers quoted in the article were optimistic that the intervention would prove successful in reducing HIV transmissions rates. The article headline read: "A *Preemptive* Strike against HIV."152 An analytics of PrEP as security therefore, might consider in more depth the role of the security discourse (including, but not limited to language) and its

<sup>&</sup>lt;sup>150</sup> Ibid., 11.

<sup>151</sup> Ibid., 127. Emphasis added.
152 Cassandra Willyard, "A Preemptive Strike against HIV," *Nature Medicine*, 15 (2009): 126 -129.

corresponding logics in how public health institutions, the pharmaceutical company, regulatory agencies, and public press have discussed PrEP, both prior to and since its market approval (for example, the use of "preemption" to describe PrEP).

As argued in the introduction of this thesis, security logics depend on a version of the future that is contingent and radically uncertain; nevertheless, they aim to render it actionable in the present. PrEP attempts to manage several uncertain futures: 1) an individual's (a) future risk behaviors and (b) potential exposure to and subsequent HIV infection and 2) the future growth of the HIV epidemic in the domestic population and on a global scale—both which are interdependent as well as contingent on a myriad of external factors. Even when research studies focus on situations where exposure is like to occur (e.g., in the case of serodiscordant couples), the infectivity of HIV (likelihood that transmission and infection will occur) estimated by each study varies greatly. An analysis of PrEP as security, therefore, must elucidate the technologies used to render this contingent future governable, as well as their assumptions about that future, individual behavior, and specific populations.

Furthermore, PrEP can be analyzed as a technology aimed at constructing resilient subjects and bodies out of those most vulnerable to HIV. Recently, critiques of the deficit-based approach (which focus on determining risk factors) to HIV prevention have arisen within the public health field itself, with a call for incorporating resilience-based approaches into research and interventions, particularly among those populations who remain at high-risk for HIV.<sup>155</sup> The concept of resilience in public health, according to

Infectious Diseases 8, no.9 (October 2010): 553.

<sup>154</sup> For example, in a meta-analysis of studies of heterosexual infectivity, Powers and colleagues conclude that: "Infectivity estimates were very heterogeneous, ranging from zero transmissions after more than 100 penile-vaginal contacts in some serodiscordant couples to one transmission for every 3.1 episodes of heterosexual anal intercourse." Kimberly Powers, Charles Poole, Audrey Pettifor, and Myron Cohen, "Rethinking the Heterosexual Infectivity of HIV-1: A Systematic Review and Meta-analysis," *The Lancet* 

<sup>&</sup>lt;sup>155</sup>Amy Herrick, Ron Stall, Hilary Goldhammer, James E. Egan, and Kenneth H. Mayer. "Resilience as a Research Framework and as a Cornerstone of Prevention Research for Gay and Bisexual Men: Theory and Evidence," *AIDS and Behavior* 18, no. 1 (January 2014): 1-9.

Herrick and colleagues, includes two primary components: "Positive adaption in the face of adversity and risk," and resilience as process, that is, as a quality that can be learned and developed over time.<sup>156</sup> Resilience-based approaches to HIV prevention seek to identify the capacities and qualities that enable individuals to avoid HIV infection, despite conditions and practices that place them at higher risk, then designing interventions to strengthen these assets and increase their prevalence among similar populations.

Commenting on research that demonstrated that the majority of gay men (in the study population) who had multiple health problems had managed to avoid HIV infection and risky sexual practices, Herrick and colleagues concluded: "For these individuals to be able to withstand persistent cultural marginalization and avoid the natural sequelae of those experiences indicates remarkable resilience and strength within this population."157 What this points to, therefore, is that future research should investigate PrEP as a method by which individuals may "avoid the natural sequelae" of their behavior and conditions of life, and as a way in which resilience is now embodied at the molecular level.

### **QUESTIONING THE "TRUTH" OF PREP AND HIV SELF-TESTING**

In their critique of resilience, Brad Evans and Julian Reid argue that in expecting subjects to develop and bolster their adaptive capacities, "building resilient subjects involves the deliberate disabling of the political habits, tendencies, and capacities . . . resilient subjects, in other words, have accepted the imperative not to resist or secure themselves from the dangers they face. Nor are they capable of viewing the world beyond the catastrophic." Resilience, they argue, actively promotes a "marginal life," incapable of imagining a politics outside of liberal governance. <sup>159</sup> Drawing from political

61

 $<sup>^{156}</sup>$  Ibid., 2.  $^{157}$  Amy Herrick et al., "Resilience as an Resource in Behavioral Intervention Design for Gay Men." AIDS and Behavior 15, no. 1 (April 2011): 26. Italics mine.

<sup>158</sup> Evans and Reid, *Resilient Life*, 42. 159 Ibid. 83.

philosopher Roberto Esposito's work on biopolitics and immunity,<sup>160</sup> Evans and Reid make an important intervention when they argue that contemporary biopolitics, with its violent interventions in the name of securing life, forgoes concern for the quality of life in favor of its survivability:

Anyone who has experienced immunization will appreciate the violence of the encounter. The whole process begins with the awareness of some vaguely looming threat which promises in the worst case an extremely violent ending. To pre-empt this happening, the subject is physically penetrated by the alien body with a controlled level of the lethal substance, which, although producing violent sickness, is a fate less than death. Such violence unto oneself offers to counter violence with violence such that life may carry on living in spite of the dangers we are incapable of securing ourselves against. It is to give over to a form of self-harm albeit in a way that is actively desired and positively conceived.<sup>161</sup>

Pre-exposure prophylaxis for HIV seems to follow a similar logic. Thus, we might ask: what impact will the widespread prophylactic use of antiretrovirals have on our collective capacity to imagine other forms of prevention that might be less violent, given the PrEP's potential to cause side-effects, drug-resistance (should a person become infected with HIV while on the drug), and unknown long-term effects, not to mention its financial costs?<sup>162</sup>

As Jennifer Fosket notes, biomedicalization most often privileges technoscientific paradigms for disease and minimizes the social context. In her analysis of chemoprevention for breast cancer, this means that the source of risk became focused on the individual body instead of the environment. She argues: "Such an approach potentially shifts attention away from efforts at identifying and eliminating the elements that put women at risk for breast cancer in the first place." One might also ask, therefore: what exactly does PrEP intend to treat? If, as it has been widely

62

<sup>&</sup>lt;sup>160</sup> Roberto Esposito, *Immunitas: The Protection and Negation of Life* (Cambridge, UK: Polity, 2011).

<sup>&</sup>lt;sup>161</sup> Evans and Reid, Resilient Life, 110.

Denise Grady, "Taking Truvada to Prevent HIV Also Comes with Risks," *New York Times*, May 14, 2012, accessed July 4, 2015, http://www.nytimes.com/2012/05/15/health/policy/taking-truvada-to-prevent-hiv-also-comes-with-risks.html.

<sup>&</sup>lt;sup>163</sup> Fosket, "Breast Cancer Risk as Disease," 349.

acknowledged, structural factors, such as poverty, political and social marginalization, gender and sexual discrimination, among others, contribute to individual risk and risk behaviors, then might PrEP detract from these environmental factors by focusing on ameliorating their effects? In that case, PrEP does not only seek to "treat" an individual's risky behavior, but attempts to minimize the effects of structural inequalities with a pharmaceutical intervention.

That an individual or population is more likely to acquire HIV is not a given. People are not inherently vulnerable to HIV, but instead that vulnerability arises out of a host of factors not of one's own, including socio-economic inequalities, histories of structural violence, and current neoliberal ideology and practices that would have us believe that these unequal conditions of life are "natural sequelae" of human existence on this planet. Like Evans and Reid, by proposing a critique of resilience approaches to HIV/AIDS prevention, I am less concerned about questioning the "truth" of HIV risk for populations marked as vulnerable, but, instead, I question the effects that truth has on the differential value ascribed to their lives, as well as how we all respond to that vulnerability.<sup>164</sup> A fuller analysis of the relationship between security, resilience, and HIV prevention would remain cognizant of these concerns.

Rose notes that "strategies for making up biological citizens 'from above' tend to represent the science itself as unproblematic." This unproblematic representation is clear from the manufacturer and public health discourse surrounding the rapid home HIV test. Yet, as this analysis has shown, scientific technologies are not neutral, and self-testing contributes to the moral and social fabric through which contemporary citizenship practices are woven. The deployment and moral valence associated with this test, as demonstrated, carries a number of significant implications for biological citizens. First, while it is framed as promoting citizen choice and autonomy, rapid home HIV testing

<sup>&</sup>lt;sup>164</sup> Evans and Reid, *Resilient Life*, 144.

represents "symbolic demedicalization." That is, it reinforces medicalization by bringing patients into contact with health authority as early as possible. It is hoped that this will translate into earlier treatment and better outcomes for HIV patients. Second, stratification of access may contradict the reasoning behind releasing the test; that is, it may be inaccessible to certain populations who, according to public health discourse, need it most. Third, efforts to test the general population, of which the new test is a component, have created a new category of biocitizens: the untested bodies.

Stratification of access may further the moral sigma against this population. In addition, the responsibility of health surveillance, as demonstrated by the potential screening of partners with the new HIV test, has been extended to monitoring others. However, this is not merely an example of pervasive biopower; biological citizens construct themselves while negotiating the use of these tests and in contradiction to their stated use.

The history and uptake of pre-exposure prophylaxis requires more in-depth analysis in order to fully comprehend its significance. Nevertheless, as a practice of biological citizenship, I argue that PrEP aims to construct resilient, responsible subjects out of those deemed most vulnerable to HIV. However, as in the case of the rapid self-test, its projected impact on reducing the overall incidence of HIV may not be realized, since many in populations at highest risk for HIV may not engage with the health care system in the way that PrEP's prescription requires. Furthermore, in biomedicalizing risk behavior and promoting resilience, interventions like PrEP can normalize and obscure structural factors that contribute significantly to heightened vulnerability to HIV. Thus, as a technology of biomedicalization, PrEP represents both the potential of technoscientific innovations and biological citizenship, as well as their exclusionary, biopolitical tendencies.

These technologies of HIV prevention present a significant shift in the way that citizens are able to understand the conditions of their bodies both outside and within the clinical setting. In addition, they can potentially improve health outcomes of biological

citizens. It is important to recognize, however, that underneath the rhetoric used to promote these medical technologies, there are important consequences for the way we monitor our own bodies and those of others, for relations of power in society, the unequal distribution of health and illness, as well as for the reach of medical authority in the private domain.

### **EPILOGUE**

Liberalism in America is a whole way of being and thinking . . . American neoliberalism still involves, in fact, the generalization of the economic form of market. It involves generalizing it throughout the social body and including the whole of the social system not usually conducted through or sanctioned by monetary exchanges.

-Michel Foucault<sup>165</sup>

Neoliberalism works by colonizing the field of value—reducing all social values to one market value—exhausting alternative social projects by denying them sustenance.

—Elizabeth Povinelli<sup>166</sup>

The work presented in this thesis is a response, in part, to the intensification of neoliberal governance that has had serious repercussions for both health care and scholarship in the humanities and social sciences in recent years. Over the past several decades, in the United States and elsewhere, the role of the public university has been dramatically re-envisioned towards a market-based, profit-oriented business model, with a focus on management and accountability and the associated "virtues" of individualism and competitiveness. Many humanities departments have found it difficult to demonstrate their productivity and value while adopting market-based practices. However, as Colleen Lye, Christopher Newfield, and James Vernon argue in a recent essay, what is occurring, more precisely, is not that humanities departments are failing the market, but, instead, by having their value assessed in solely monetary terms, "they are being subjected to market failure." 168

Michel Foucault, *The Birth of Biopolitics: Lectures at the College de France 1978-1979*.
 Edited by Michael Senellart, translated by Graham Burcheli. New York, NY: Picador, 2008. 218, 243.
 Elizabeth Povinelli, *Economies of Abandonment*, 134.

<sup>&</sup>lt;sup>167</sup> Henry A. Giroux, "Bare Pedagogy and the Scourge of Neoliberalism: Rethinking Higher Education as a Democratic Public Sphere," *The Educational Forum* 74, no 3 (2010): 184-196.

<sup>&</sup>lt;sup>168</sup> Colleen Lye, Christopher Newfield and James Vernon, "Humanists and the Public University," *Representations* 116, no. 1 (Fall 2011): 7.

In this climate of fiscal insecurity, academics (including students) of many fields have been tasked with adapting to the neoliberal university, to become more resilient. Brad Evans and Julian Reid begin their work Resilient Life: The Art of Living Dangerously by questioning the political stakes of being academically resilient. "To operate in the academy today . . ." they note, "is to be as vulnerable as anybody else in late liberal society. Any principles about reclaiming the meaning of the University as such go out of the window as we are told to accept the intellectual realities of the times." They argue, as noted in this thesis, that resilience-building ideologies aim to preclude the possibility of meaningful political resistance or critique, since resilient subjects must first accept the certainty of their vulnerability and the catastrophic future. For those who have embraced critique, to accept the world as represented contradicts their ethical orientation to that world. The casualties that result from surviving in such an environment are numerous. Foucault observed that with biopower the extermination of life "presents itself as the counterpart of a power that exerts a positive influence on life." However, these "lethal conditions" of late liberal regimes do not only produce biological or political deaths; as Povinelli argues, our scholarly attachments can be extinguished and/or exhausted as well. 171 These ideas, collaborations, and projects that are tabled indefinitely or denied support are also the casualties of neoliberal biopolitics. The challenge that many face today, therefore, within and outside the academy, is not the will to be otherwise, but the will to imagine that otherwise is even possible.

Given the scope of this thesis and other constraints, I have called into question several core assumptions and practices of HIV prevention without offering viable alternatives. Yet, to say "not this" without offering a "what then," as Povinelli notes, is still productive. "'Not this' makes a difference even if it does not immediately produce a

<sup>&</sup>lt;sup>169</sup> Reid and Evans, Resilient Life, xiv.

<sup>&</sup>lt;sup>170</sup> Foucault, *The History of Sexuality, Vol. 1,* 137. Povinelli, *Economies of Abandonment,* 152.

propositional otherwise," she argues; by pointing out the contradictions between "what is claimed and what is, and the techniques of power that allow the claimed world to appear not merely as the actual world but the best of all actual worlds," critique can make our identification with that claimed world "unworkable." <sup>172</sup> By destabilizing the normative world, such critique makes alternative ways of being possible (or even thinkable).

I began this thesis by discussing the Ursula Le Guin's philosophical fiction "The Ones Who Walk Away from Omelas." Le Guin ends the story with an enigmatic, poetic scene. Every so often, after an adolescent witnesses the suffering on which the city's happiness depends, instead of returning home, he or she continues walking, exiting the city. The same happens occasionally with certain older inhabitants, who, after a day of silence, leave the city as well. Le Guin closes her tale:

Each alone, they go west or north, towards the mountains. They go on. They leave Omelas, they walk ahead into the darkness, and they do not come back. The place they go towards is a place even less imaginable to most of us than the city of happiness. I cannot describe it at all. It is possible that it does not exist. But they seem to know where they are going, the ones who walk away from Omelas.<sup>173</sup>

For those who find it impossible to reconcile what has been promised by the normative world with their being in it, and who find its casualties unacceptable, sometimes the most politically productive act is to say "not this" even when an alternative is not readily visible. Those who "leave" in this way may not completely exit the realm of biopolitics, but through critique, they are willing to imagine other ways of being in the world that are less violent, less dependent on the exclusion of others from the realm of humanity.

<sup>&</sup>lt;sup>172</sup> Ibid., 191.

<sup>&</sup>lt;sup>173</sup> Le Guin, "The Ones Who Walk Away From Omelas," 284.

# **Bibliography**

- Anderson, Ben. "Preemption, Precaution, Preparedness: Anticipatory Action and Future Geographies." *Progress in Human Geography* 34, no. 6 (December 1, 2010): 777–798.
- Anderson, Jessica Cumberbatch. "Magic Johnson: OraQuick, the First At-Home HIV Test, Is 'A Game Changer." *Huffington Post*. October 15, 2012. Accessed May 16, 2015. http://www.huffingtonpost.com/2012/10/15/magic-johnson-oraquick-hiv-home-test-game-changer.
- Arnold, Carrie. "At-home HIV Test Poses Dilemmas and Opportunities." *The Lancet* 380, no. 9847 (September 22, 2012): 1045–1046.
- Aveline, David Timothy. "A Typology of Perceived HIV/AIDS Risk-reduction Strategies Used by Men Who 'Cruise' Other Men for Anonymous Sex." *Journal of Sex Research* 32, no. 3 (1995): 201–212.
- Baeten, Jared M., Jessica E. Haberer, Albert Y. Liu, and Nirupama Sista. "Preexposure Prophylaxis for HIV Prevention: Where Have We Been and Where Are We Going?" *Journal of Acquired Immune Deficiency Syndrome* 63, no. 2 (July 2013): S122–S129.
- Barad, Karen. "Posthumanist Performativity: Toward an Understanding of How Matter Comes to Matter." *Signs: Journal of Women in Culture and Society* 28, no. 3 (Spring 2003): 801-831.
- Barker, Kezia, Sarah L. Taylor, and Andrew Dobson. "Introduction: Interrogating Bioinsecurities." In *Biosecurity: The Socio-politics of Invasive Species and Infectious Diseases*, edited by Andrew Dobson, Kezia Barker, and Sarah L. Taylor. New York, NY: Routledge, 2013. 3-28.
- Bethge, Phillip. "Tech Pioneers Track Bodily Functions Day and Night." *Spiegel Online*. January 5, 2012. Accessed May 16, 2015. http://www.spiegel.de/international/world/new-trend-towards-self-monitoring-using-high-tech-equipment-a-829454.html.
- "Blood Collection Kits Labeled for Human Immunodeficiency Virus Type 1 (HIV-1) Antibody Testing; Home Test Kits Designed to Detect HIV-1 Antibody; Open Meeting," *Federal Register* 50 (February 17, 1989): 7279.
- Branson, Bernard M., H. Hunter Handsfield, Margaret A. Lampe, Robert S. Janssen, Allan W. Taylor, Sheryl B. Lyss, and Jill E. Clark. "Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-care Settings." *MMWR Recommendations and Reports* 55 (September 22, 2006): 1–17.

- Braun, Bruce. "Power over Life: Biosecurity as Biopolitics." In *Biosecurity: The Socio- politics of Invasive Species and Infectious Diseases*, edited by Andrew Dobson, Kezia Barker, and Sarah L. Taylor. New York, NY: Routledge, 2013. 45-57.
- Buse, Ken, and Gill Walt. "Global Public-private Partnerships: Part I A New Development in Health?" *Bulletin of the World Health Organization* 78, no. 4 (2000): 549-61.
- Butler, Judith. "What is Critique? An Essay on Foucault's Virtue." *Transversal* (May 2001). Accessed May 15, 2015. http://eipcp.net/transversal/0806/butler/en.
- Campbell, Sheldon, and Roger Klein. "Home Testing To Detect Human Immunodeficiency Virus: Boon or Bane?" *Journal of Clinical Microbiology* 44, no. 10 (October 2006): 3473–3476.
- Carballo-Diéguez, Alex, Timothy Frasca, Ivan Balan, Mobolaji Ibitoye, and Curtis Dolezal. "Use of a Rapid HIV Home Test Prevents HIV Exposure in a High Risk Sample of Men Who Have Sex With Men." *AIDS and Behavior* 16, no. 7 (October 2012): 1753–1760.
- Centers for Disease Control and Prevention (CDC). "HIV and AIDS in the United States by Geographic Distribution Fact Sheet." June 2012. Accessed May 16, 2015. http://www.cdc.gov/hiv/resources/factsheets/geographic.htm.
- —. "Pre-exposure Prophylaxis (PrEP)." June 25, 2015. Accessed July 4, 2015. http://www.cdc.gov/hiv/prevention/research/prep/.
- —. Pre-exposure Prophylaxis for the Prevention of HIV Infection in the United States—2014: A Clinical Practice Guideline. Atlanta, GA: CDC, 2014. Accessed May 16, 2015. http://www.cdc.gov/hiv/pdf/PrEPguidelines2014.pdf.
- —. "Talk to Your Doctor About PrEP." Accessed May 12, 2015. http://www.cdc.gov/hiv/pdf/risk PrEP TalkingtoDr.pdf.
- Cheek, Julianne. "Foucauldian Discourse Analysis." In *The SAGE Encyclopedia of Qualitative Research Methods*, Vol. I, edited by Lisa M. Given, 355-357. Thousand Oaks, CA: SAGE Publications, 2008.
- Clarke, Adele E., Janet K Shim, Laura Mamo, Jennifer Ruth Fosket, and Jennifer R. Fishman. "Biomedicalization: A Theoretical and Substantive Introduction." In *Biomedicalization: Technoscience, Health, and Illness in the U.S.*, edited by Adele E. Clarke, Jennifer Ruth Fosket, Laura Mamo, Jennifer R. Fishman, and Janet K. Shim, 1-46. Durham, NC: Duke University Press, 2010.

- —. "Biomedicalization: Technoscientific Transformations of Health, Illness, and U.S. Biomedicine." In *Biomedicalization: Technoscience, Health, and Illness in the U.S.*, edited by Adele E. Clarke, Jennifer Ruth Fosket, Laura Mamo, Jennifer R. Fishman, and Janet K. Shim, 47-87. Durham, NC: Duke University Press, 2010.
- Conrad, Peter. "Medicalization and Social Control." Annual Review of Sociology 18, no. 1 (1992): 209–232.
- "Consent and Legal Agreement." 23andMe. Accessed April 5, 2015. https://www.23andme.com/about/consent/?version=1.3.
- Cooper, Melinda. *Life as Surplus: Biotechnology and Capitalism in the Neoliberal Era.* Seattle, WA: University of Washington Press, 2008.
- Cruikshank, Barbara. *The Will to Empower: Democratic Citizens and Other Subjects*. Cornell, NY: Cornell University Press, 1999.
- Denning, Paul and Elizabeth DiNenno. "Communities in Crisis: Is There a Generalized HIV Epidemic in Impoverished Urban Areas of the United States?" XVIII International AIDS Conference. July 18-23, 2010. Accessed May 16, 2015. http://hivandhepatitis.com/2010\_conference/AIDS2010/docs/0723e\_2010.html.
- Dillon, Michael. "Underwriting Security." *Security Dialogue* 39, no. 2-3 (April 2008): 309-332.
- Duncan, Ian. "Drugstores Soon Will Sell Tests for HIV." *Star Tribune*. July 3, 2012. Accessed May 16, 2015. http://www.startribune.com/lifestyle/health/161302315.html.
- Elbe, Stefan. *Virus Alert: Security, Governmentality, and the AIDS Pandemic.* New York, NY: Columbia University Press, 2009.
- Esposito, Roberto. *Bios: Biopoltics and Philosophy*. Minneapolis, MN: University of Minnesota Press, 2008.
- —. *Immunitas: The Protection and Negation of Life.* Cambridge, UK: Polity, 2011.
- Evans, Brad and Julian Reid. "Dangerously Exposed: The Life and Death of the Resilient Subject." *Resilience: International Policies, Practices and Discourses* 1, no. 2 (2013): 83-98.
- —. Resilient Life: The Art of Living Dangerously. Cambridge, UK: Polity Press, 2014.
- Farmer, Paul. "An Anthropology of Structural Violence." *Current Anthropology*, 45, no. 3 (Jun 2004): 305-317.

- Food and Drug Administration (FDA). "Transcript of 102nd Meeting of the Blood Products Advisory Committee (BPAC)." May 15, 2012. Accessed May 16, 2015. http://www.fda.gov/downloads/AdvisoryCommittees/CommitteesMeetingMateria ls/BloodVaccinesandOtherBiologics/BloodProductsAdvisoryCommittee/UCM309516.pdf
- Food and Drug Administration Blood Products Advisory Committee (BPAC). "Testimony of Elliot J. Millenson." March 10, 2006. Accessed July 4, 2015. http://www.fda.gov/ohrms/dockets/ac/06/slides/2006-4206OPH2 2b.pdf.
- Fosket, Laura. "Breast Cancer Risk as Disease." In *Biomedicalization: Technoscience, Health, and Illness in the U.S.*, edited by Adele E. Clarke, Jennifer Ruth Fosket, Laura Mamo, Jennifer R. Fishman, and Janet K. Shim. Durham, NC: Duke University Press, 2010. 331-352.
- Foucault, Michel. *The Birth of Biopolitics: Lectures at the College de France 1978-1979*. Translated by Graham Burcheli. New York, NY: Picador, 2008.
- —. *The History of Sexuality* Vol. 1. Translated by Robert Hurley. New York, NY: Vintage, 1980.
- —. The Order of Things: An Archaeology of the Human Sciences. London, UK: Tavistock Publications, 1970.
- —. "Society Must Be Defended": Lectures at the Collège de France, 1975-Translated by David Macey. London, UK: Penguin, 2003.
- —. "The Subject and Power." Critical Inquiry 8, no. 4 (Summer 1982): 777-795.
- Gilead Sciences. "About Truvada for PrEP Indication." June 2014. Accessed July 6, 2015. http://www.truvadapreprems.com/pre-exposure-prophylaxis.
- Giroux, Henry A. "Bare Pedagogy and the Scourge of Neoliberalism: Rethinking Higher Education as a Democratic Public Sphere." *The Educational Forum* 74, no 3 (2010): 184-196.
- Golub, Sarit A., Don Operario, and Pamina M. Gorbach. "Pre-exposure Prophylaxis State of the Science: Empirical Analogies for Research and Implementation." *Current HIV/AIDS Reports* 7, no. 4 (November 2010): 201-209.
- Grady, Denise. "Taking Truvada to Prevent HIV Also Comes with Risks." *New York Times*. May 14, 2012. Accessed July 4, 2015. http://www.nytimes.com/2012/05/15/health/policy/taking-truvada-to-prevent-hiv-also-comes-with-risks.html.

- Greaney, Anna-Marie, Dónal O'Mathúna, and P. Anne Scott. "Patient Autonomy and Choice in Healthcare: Self-testing Devices as a Case in Point." *Medicine, Health Care, and Philosophy* 15, no.4: 383–395.
- Halperin, Karin. "Home Testing for HIV—Reading the Lines in Do-It-Yourself Test." *ABC News*. December 18, 2012. Accessed May 16, 2015. http://abcnews.go.com/ Health/hiv-home-testing-oraquick-hits-stores-raises-questions.
- Herrick, Amy, Sin How Lim, Chongyi Wei, Helen Smith, Thomas Guadamuz, Mark S Friedman, and Ron Stall. "Resilience as an Untapped Resource in Behavioral Intervention Design for Gay Men." *AIDS and Behavior* 15, no. 1 (April 2011): 25-29.
- Herrick, Amy, Ron Stall, Hilary Goldhammer, James E. Egan, and Kenneth H. Mayer. "Resilience as a Research Framework and as a Cornerstone of Prevention Research for Gay and Bisexual Men: Theory and Evidence." *AIDS and Behavior* 18, no. 1 (January 2014): 1-9.
- Holmes, David. "The US Treads Carefully with PrEP." *Lancet* 12, no. 7 (July 2012): 515-516.
- Homeland Security Council. *National Strategy for Homeland Security*. Washington, DC: Homeland Security Council, 2007. Accessed May 16, 2015. http://www.dhs.gov/xlibrary/assets/nat\_strat\_homelandsecurity\_2007.pdf.
- Horn, Jaqueline, and Jane Chetwynd. "Changing Sexual Practices amongst Homosexual Men in Response to AIDS: Who Has Changed, Who Hasn't and Why?" Report to the New Zealand Department of Health, September 1989.
- Howard, Heidi Carmen, and Pascal Borry. "Is There a Doctor in the House?: The Presence of Physicians in the Direct-to-Consumer Genetic Testing Context." *Journal of Community Genetics* 3, no. 2 (April 2012): 105-117.
- Howell, Alison. "Resilience as Enhancement: Governmentality and Political Economy beyond 'Responsibilisation." *Politics* 35, no. 1 (February 2015): 67–71.
- Joint United Nations Programme on HIV and AIDS (UNAIDS). "An HIV Test in the Privacy of Your Own Home." July 4, 2012. Accessed May 16, 2015. http://www.unaids.org/en/resources/presscentre/featurestories/2012/july/20120704hometesting/.
- Joseph, Jonathan. "Resilience as Embedded Neoliberalism: A Governmentality Approach," *Resilience: International Policies, Practices and Discourses* 1, no. 1 (2013): 38-52.

- Kline, Wendy. *Bodies of Knowledge: Sexuality, Reproduction, and Women's Health in the Second Wave.* Chicago, IL: University of Chicago Press, 2010.
- Koenig, Linda J., Cynthia Lyles, and Dawn K. Smith. "Adherence to Antiretroviral Medications for HIV Pre-Exposure Prophylaxis." *American Journal of Preventive Medicine* 44, no. 1: S91 S98.
- Kretowicz, Ewa. "HIV Groups Want Home Testing Kit in Australia." *Sydney Morning Herald*. July 8, 2012. Accessed May 16, 2015 http://www.smh.com.au/national/health/hiv-groups-want-home-testing-kit-in-australia-20120707-21nqr.html.
- Lakoff, Andrew. "From Population to Vital System: National Security and the Changing Object of Public Health." In *Biosecurity Interventions: Global Health and Security in Practice*, edited by Andrew Lakoff and Stephen Collier, 33-59. New York: Columbia University Press, 2008.
- Leavitt, Sarah. "A Private Little Revolution': The Home Pregnancy Test in American Culture." *Bulletin of the History of Medicine* 80, no. 2 (Summer 2006): 317-345.
- Le Guin, Ursula. "The Ones Who Walk Away from Omelas." In *The Wind's Twelve Quarters*, 275-284. New York, NY: Harpers & Row, 1975.
- Lentzos, Filippa, and Nikolas Rose. "Governing Insecurity: Contingency Planning, Protection, Resilience." *Economy and Society* 38, no. 2 (May 2009): 230-254.
- Lewis, Carol. "Home Diagnostic Tests: The Ultimate House Call?" *FDA Consumer* 35, no. 6 (November/December 2001): 18-22.
- Lupton, Deborah. Risk. 2nd ed. New York, NY: Routledge, 2013.
- —. "Risk and Emotion: Towards an Alternative Theoretical Perspective." *Health, Risk & Society 15*, no. 8 (2013): 634-647.
- —. "Risk as Moral Danger: the Social and Political Functions of Risk Discourse in Public Health." *International Journal of Health Services* 23, no. 3 (July 1993): 425–443.
- Lye, Colleen, Christopher Newfield, and James Vernon. "Humanists and the Public University." *Representations* 116, no. 1 (Fall 2011): 1-18.
- Madison, D. Soyini. *Critical Ethnography: Methods, Ethics, and Performance*. 2nd ed. Thousand Oaks, CA: Sage Publications, 2012.
- Mamo, Laura. *Queering Reproduction: Achieving Pregnancy in the Age of Technoscience*. Durham, NC: Duke University Press, 2007.

- Massumi, Brian. "Potential Politics and the Primacy of Preemption." *Theory & Event* 10, no. 2 (2007). Accessed May 16, 2015. http://muse.jhu.edu/journals/theory\_and\_event/v010/10.2massumi.html
- Mavedzenge, Sue Napierala, Rachel Baggaley, and Elizabeth L. Corbett. "A Review of Self-Testing for HIV: Research and Policy Priorities in a New Era of HIV Prevention." *Clinical Infectious Diseases: An Official Publication of the Infectious Diseases Society of America* 57, no. 1 (July 2013): 126–38.
- McGregor, Susan. "Neoliberalism and Health Care." *International Journal of Consumer Studies* 25, no. 2 (June 2001): 82-89.
- McNeil Jr., Donald. "OraQuick At-Home H.I.V. Test Wins F.D.A. Approval." *New York Times*. July 3, 2012. Accessed May 16, 2015. http://www.nytimes.com/2012/07/04/health/oraquick-at-home-hiv-test-wins-fda-approval.html.
- —. "Another Use for Home H.I.V. Test: Screening Partners." *New York Times*. October 5, 2012. Accessed May 16, 2015. http://www.nytimes.com/2012/10/06/health/another-use-for-home-hiv-test-screening-partners.html.
- Mol, Annmarie. *The Body Multiple: Ontology in Medical Practice*. Durham, NC: Duke University Press, 2002.
- Morone, James A. "Enemies of the People: The Moral Dimension to Public Health." *Journal of Health Politics, Policy and Law.* 22, no. 4 (August 1997): 993-1020.
- Nguyen, Vinh-Kim. "Antiretroviral Globalism, Biopolitics, and Therapeutic Citizenship." *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*, edited by Aihwa Ong and Stephen J. Collier. Oxford, UK: Blackwell Publishing, 2004. 124–144.
- O'Malley, Pat. "Resilient Subjects: Uncertainty, Warfare and Liberalism." *Economy and Society* 39, no. 4 (November 2010): 488-509.
- "OraQuick Television Advertisement." YouTube video. 0:43. Posted by *Orasure*. December 2012. Accessed July 4, 2013. http://www.youtube.com/watch?feature.player\_detailpage&v.82rV3jgg-Hk.
- "OraSure Technologies' CEO Presents OraQuick In-Home HIV Test (Transcript)." *Seeking Alpha*. October 10, 2012. Accessed May 16, 2015. http://seekingalpha.com/article/917691-orasure-technologies-ceo-presents-oraquick-in-home-hiv-test-transcript?source=nasdaq.

- Paltiel, A. David, and Harold Pollack. "Price, Performance, and the FDA Approval Process: The Example of Home HIV Testing." *Medical Decision Making* 30, no. 2 (March/April 2010): 217–223.
- Pant Pai, Nitika, Jigyasa Sharma, Sushmita Shivkumar, Sabrina Pillay, Caroline Vadnais, Lawrence Joseph, Keertan Dheda, and Rosanna W. Peeling. "Supervised and Unsupervised Self-Testing for HIV in High-and Low-Risk Populations: A Systematic Review." *PLoS Medicine* 10, no. 4 (April 2013). Accessed May 16, 2015. http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1001414.
- Petersen, Alan, and Deborah Lupton. *The New Public Health: Health and Self in the Age of Risk.* Thousand Oaks, CA: Sage Publications, 1997.
- Pollack, Andrew. "Gene Testing Questioned by Regulators." *New York Times*. June 26, 2008. Accessed May 16, 2015. http://www.nytimes.com/2008/06/26/business/26gene.html.
- Povinelli, Elizabeth. *Economies of Abandonment: Social Belonging and Endurance in Late Liberalism*. Durham N.C.: Duke University Press, 2011.
- Powers, Kimberly, Charles Poole, Audrey Pettifor, and Myron Cohen. "Rethinking the Heterosexual Infectivity of HIV-1: A Systematic Review and Meta-analysis." *The Lancet Infectious Diseases* 8, no.9 (October 2010): 553–563.
- Pryce, Anthony. "Frequent Observation: Sexualities, Self-surveillance, Confession and the Construction of the Active Patient." *Nursing Inquiry* 7, no. 2 (June 2000): 103–111.
- Rose, Nikolas. "Governing 'Advanced' Liberal Democracies." In *Foucault and Political Reason*, edited by Andrew Barry, Thomas Osbourne, and Nikolas Rose. Chicago, IL: University of Chicago Press, 1996. 37-64.
- —. "The Politics of Life Itself." *Theory, Culture, and Society* 18, no. 6 (December 2001): 1-30.
- —. The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century. Princeton, NJ: Princeton University Press, 2007.
- Rose, Nikolas and Carlos Novas. "Biological Citizenship." In *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems,* edited by Aihwa Ong and Stephen J. Collier, 439-462. Oxford, UK: Blackwell Publishing, 2004.
- Tone, Andrea. "Medicalizing Reproduction: The Pill and Home Pregnancy Tests." *Journal of Sex Research* 49 no. 4 (2012): 319-327.

- Waldby, Catherine. AIDS and the Body Politic. New York, NY: Routledge, 1996.
- Walker, Jeremy, and Melinda Cooper. "Genealogies of Resilience: From Systems Ecology to the Political Economy of Crisis Adaptation." *Security Dialogue* 42 no. 2 (April 2011): 143-160.
- Wallace, Kenyon. "Health Canada Mum on Future Availability of In-home Oral HIV Test." *Toronto Star.* July 4, 2012. Accessed May 16, 2015. http://www.thestar.com/news/canada/2012/07/04/health\_canada\_mum on future availability of inhome oral hiv test.html.
- Whellams, Melissa. "The Approval of Over-the-counter HIV Tests: Playing Fair When Making the Rules." *Journal of Business Ethics* 77, no. 1 (January 2008): 5-15.
- Willyard, Cassandra. "A Preemptive Strike against HIV." *Nature Medicine* 15 (2009): 126 129.
- —. "Recommendation of HIV Test Brings Diagnostic Dilemma Home." *Nature Medicine* 18, no. 6 (June 2012): 841.
- World Health Organization (WHO). "Report on the First International Symposium on Self-testing for HIV: The Legal, Ethical, Gender, Human Rights and Public Health Implications of Self-testing Scale-up." Geneva, SZ: World Health Organization, 2013. Accessed May 16, 2015. http://who.int/hiv/pub/vct/self\_test/en/index.html.
- Wright, Alexi A., and Ingrid T. Katz. "Home Testing for HIV." *New England Journal of Medicine* 354, no. 5 (2006): 437-440.

#### Vita

Jonathan Banda was born in Wichita Falls, Texas on January 2, to Joseph and Minerva Banda. Before studying at UTMB, he was the coordinator of an institutional review board at the University of California, Berkeley.

#### Education

B.A. (Latin American Studies) and B.S. (International Economics), May 2004, Texas Christian University, Fort Worth, Texas

# **Teaching**

UTMB School of Medicine, July-Aug 2013: Teaching assistant/co-facilitator, *Humanities*, *Ethics*, *and Professionalism* (*HEP*), Practice of Medicine 2.

UTMB School of Medicine, May-June 2014: Co-instructor, Joint Admissions Medical Program (JAMP) short course in medical humanities and creative expression.

University of Houston (The Honors College), August 2014-December 2014: Teaching assistant, *Readings in Medicine and Society* (HON 3301).

### **Publications**

Brody, Howard, Sharon Croisant, Jerome Crowder, and <u>Jonathan Banda</u>. "Ethical Issues in Patient-Centered Outcomes Research and Comparative Effectiveness Research: A Pilot Study of Community Dialogue." *Journal of Empirical Research on Human Research Ethics* 10, no. 1 (February 2015): 22-30. DOI: 10.1177/1556264614568426.

Banda, Jonathan. "Rapid Home HIV Testing: Risk and the Moral Imperatives of Biological Citizenship." *Body & Society*. Prepublished July 21, 2014. DOI:10.1177/1357034X14528391.

### Summary of Thesis

This thesis examines the history and social implications of the rapid self-test for HIV (brand name: OraQuick in-home HIV test) in the United States. Via a discursive analysis of literature, product packaging, and marketing and public health rhetoric surrounding the test, I identify several points of contention that have arisen with the varied, sometimes disparate interests of public health, federal regulators, and private corporations. I propose that while home HIV tests may improve health outcomes for some and appear to expand consumer rights, they are in fact the vanguard of a new form of self-testing that carries a

moral urgency to protect one's own body and to manage societal risk. This thesis concludes with a preliminary critical analysis of the prophylactic use of antiretrovirals for HIV, arguing that this practice represents a new relation of the body to risk, while potentially obscuring or normalizing structural conditions that contribute to vulnerability to infection.

Permanent address: 2115 Eagle St., Vernon, TX 76384

This thesis was typed by Jonathan Banda.