The End of AIDS: Gender, Race and Class Politics in New York's Campaign to End the Epidemic

Lauren Suchman
The Graduate Center, City University of New York

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THE END OF AIDS:
GENDER, RACE AND CLASS POLITICS IN NEW YORK’S CAMPAIGN TO END THE
EPIDEMIC

by

Lauren K. Suchman

A dissertation submitted to the Graduate Faculty in Anthropology in partial fulfillment of the
requirements for the degree of Doctor of Philosophy, The City University of New York

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Gender, Race and Class Politics in New York State’s Campaign to End the Epidemic

by

Lauren K. Suchman

This manuscript has been read and accepted for the Graduate Faculty in Anthropology in satisfaction of the dissertation requirement for the degree of Doctor of Philosophy.

__________________________________________  ________________________________________________________
Date                                             Ida Susser

Chair of Examining Committee

__________________________________________  ________________________________________________________
Date                                             Jeff Maskovsky

Executive Officer

Supervisory Committee:

Murphy Halliburton

Michael Blim

Emily Martin

THE CITY UNIVERSITY OF NEW YORK
ABSTRACT

THE END OF AIDS: GENDER, RACE, AND CLASS POLITICS IN NEW YORK’S CAMPAIGN TO END THE EPIDEMIC

by

Lauren Suchman

Adviser: Professor Ida Susser

Since its official discovery in 1981, the story of HIV/AIDS has been a story of inequality. Not only has the virus spread more easily among those marginalized due to their gender, race, or class, but AIDS activism itself has tended to elevate the voices and needs of the more powerful over those with less privilege. While we might point to 1981, when the CDC issued its first official report on HIV, as the official “beginning” of HIV/AIDS, where and how does the story end? This dissertation examines one attempt to bring the story to a close: New York State’s “Ending the Epidemic” campaign.

Based on 14 months of ethnographic fieldwork (October 2014 – December 2015) throughout New York State, this dissertation draws on participant-observation and interviews with government officials, researchers, physicians, activists, and other advocates either directly involved in or affected by the campaign to answer the question: How do the fault lines of society come out at the "end"? In addressing this question, the study draws on the theoretical literature on social activism, knowledge creation and management, pharmaceuticals, and gender, race, and sexuality to examine how inequalities are either perpetuated or transformed in the context of Ending the Epidemic. It finds that, while many longstanding inequalities are still evident in the campaign, particularly concerning women and people of color, Ending the Epidemic has also served as an opportunity for some people representing historically marginalized groups to gain a stronger voice in the field. These include, most notably, men of color who have sex with other
men. However, young people represent a group that is particularly vulnerable to HIV, but is not yet adequately engaged by Ending the Epidemic. Not having grown up with the fear of AIDS instilled in earlier generations and with little voice in high-level political platforms, young people present both a challenge and an opportunity for the Ending the Epidemic campaign to reach beyond the usual suspects and address under-recognized inequalities.
ACKNOWLEDGMENTS

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INTRODUCTION

Fred held my gaze steadily over his cup of coffee as he told me, “New York is a ghost town for us.” We were seated in a café across from Tompkins Square Park in the East Village and Fred, a prominent AIDS activist, was describing how the surrounding neighborhood was once a vibrant artistic community, much of which was wiped out by AIDS (a tale recounted by other artists, such as Patti Smith (2010)). Referring to himself and other AIDS activists who have been in the field for the past three decades, Fred suggested that they all carry the memories of friends and lovers with them, and that the work they carry out today still stems from the trauma of the early years of the epidemic. Indeed, hearkening back to those early years is a common refrain among activists who have been in the field a long time. At a recent “Hidden Histories” conference sponsored by the AIDS Coalition to Unleash Power (ACT UP), several speakers began their remarks with comments like “I’m standing here with a lot of people who are no longer here” and one noted, “For a long time, my days began with reading the obituary section of The New York Times…” In his opening speech to the New York State Ending the Epidemic Task Force, the subject of this dissertation, another prominent activist spoke of an “unseen balcony” in the room where those who had died of AIDS-related complications were seated, ostensibly watching over the proceedings as silent participants. The story of the AIDS epidemic in the U.S. is, in many respects, a ghost story.

In the mid-1980s, HIV incidence (new infections) was approximately 130,000 per year (U.S. Center for Disease Control and Prevention 2016) and by 1995 AIDS was the leading cause of death among people aged 25-44 in the United States (U.S. Centers for Disease Control and Prevention 1997). As the statements above suggest, New York City was particularly hard hit.
Although the City made up only 3% of the U.S. population at the epidemic’s height in the early 1990s, it accounted for 16% of all AIDS cases. At one point, AIDS-related deaths in New York City rose to almost 21 per day (Altman 1997).

However, AIDS is not only a story of ghosts, it is also a story of inequality. First officially reported among a group of gay white men in California (CDC 1981), the virus long went unrecognized among some populations, such as women (see Susser 2009), while a strong focus on others, such as Haitians and injection drug users (Farmer 2006; Rhodes et al. 2005; Singer 1994; Desjarlais and Friedman 1990) reflected both the race and class inequalities that put certain people at higher risk for HIV while also making them appear risky to society in and of themselves. Indeed, over the past 35 years, inequality along the lines of gender, race, ethnicity, and class have contributed both to the rapid growth of HIV/AIDS into a global epidemic and to its persistence. While HIV/AIDS prevalence in the U.S. has decreased overall since the virus was first discovered, it is no secret that communities of color have long been disproportionately affected (Friedman et al. 1987).

Globally, the virus has spread along fault lines of inequality as well. In sub-Saharan Africa, the region of the world with the highest rates of HIV infection, women bear the brunt of the disease burden, as well as the accompanying burden of care (UNAIDS 2014; Schatz & Ogunmefun 2007; Kipp et al. 2006). Even the body of scientific literature that has attempted to trace the virus to its biological origins suggests that it in fact began in Africa (Heeney, Dalgeish & Weiss 2006; Hillis 2000; Shannon, Pyle & Bashshur 1991). And although some have tried to show that AIDS has spread in the context of colonial and post-colonial exploitation (Pépin 2011), the theory is not without racist undertones of a killer disease from the depths of Joseph Conrad’s dark, savage continent (Conrad 1899).
HIV/AIDS is notable not just for the devastation it has wrought, but also for the incredible response it has garnered among people living with HIV/AIDS (PLHA). From South Africa’s Treatment Action Campaign (TAC) (Heywood 2009; Friedman and Mottiar 2005) to the AIDS Coalition to Unleash Power (ACT UP) in New York (Hubbard 2012), thousands of people have literally taken to the streets to fight for their lives. However, as I describe further below, AIDS activism in the U.S. has long suffered internally from the same inequalities that shape the epidemic on a larger scale. Groups like ACT UP have been accused of racism and sexism (Gould 2012; Gould 2002), pointing to the contradictions of AIDS activism’s relative success; how can a group of well-intentioned people do good work while simultaneously rendering other affected populations invisible?

As Joan Didion wrote in her essay “Goodbye to All That,” “It is easy to see the beginnings of things, and harder to see the ends” (1961: 225). While we might point to 1981, when the CDC issued its first official report on HIV, as the official “beginning” of HIV/AIDS, where and how does the story end? This dissertation examines one attempt to bring the story to a close: New York State’s “Ending the Epidemic” campaign. Starting with Governor Andrew Cuomo’s first announcement in June 2014 that the state would attempt to “end AIDS” by 2020, I closely follow the Ending the Epidemic Task Force from its first convening in October 2014 to its final meeting in January 2015, and the subsequent launch of the Blueprint on Ending the AIDS Epidemic in April 2015. I then trace the Ending the Epidemic “implementation” meetings held across the state during the summer and fall of 2015, concluding with the World AIDS Day celebration convened by several New York City-based advocacy groups at the famous Apollo Theater in Harlem on December 1, 2015. Through the lens of this campaign, I analyze the
current state of AIDS activism in New York to answer the question: How do the fault lines of society come out at the "end"?

In some respects this story is nothing new, as social inequalities along the lines of gender, race, and class tend to perpetuate themselves. However, certain moments in the campaign do point to spaces where the lines of inequality are softening, particularly as some campaign participants who identify with underrepresented groups (e.g. MSM of color) have gained influence and authority through their participation in Ending the Epidemic. On the other hand, young people emerge as a population that EtE should make a more forceful effort to reach. Without the healthy fear of HIV/AIDS that previous generations had and with little power to influence high-level decision making, this research suggests that young people are in great need of HIV prevention efforts, but struggle to make themselves heard in a campaign like Ending the Epidemic.

What Is an Epidemic?

The U.S. Centers for Disease Control and Prevention (CDC) define “epidemic” somewhat vaguely as “an increase, often sudden, in the number of cases of a disease above what is normally expected in that population in that area” (U.S. Department of Health and Human Services Centers for Disease Control and Prevention 2012). This same source defines “endemic” disease as “The amount of a particular disease that is usually present in a community,” begging the question, three decades into the AIDS epidemic, at what point might HIV/AIDS become an endemic disease? For the moment, New York State still considers itself to be in the midst of an “epidemic” of HIV/AIDS. This epidemic peaked in the early 1990s with approximately 15,000 new cases per year, while for the past few years the state has recorded approximately 3,000 new HIV infections per year (New York State Department of Health AIDS Institute 2013).
The vague public health definition of “epidemic” raises questions around the kind of social work this classification does for a disease. What does “epidemic” versus “endemic” disease mean? According to Rosenberg (1989), epidemics are events (rather than trends) that are highly visible and elicit an immediate and widespread response. During their course, epidemics tend to follow a “dramaturgic” form in which they “start at a moment in time, proceed on a stage limited in space and duration, follow a plot line of increasing and revelatory tension, move to a crisis of individual and collective character, then drift toward closure” (Ibid., 2), ultimately ending with “a whimper, not a bang” (Ibid., 9).

While Rosenberg’s assertion that epidemics take the form of a drama may appear to belittle a serious public health phenomenon in which many lives are lost, it is not entirely surprising given what we know about the social nature of disease. In an earlier article, Rosenberg writes, “disease is constructed, not discovered” (1986, 35), and we certainly know that suffering and healing often are social events (see for example Lindenbaum 1978; Turner 1970). Further, according to Brandt (1988), “Throughout human history, epidemic disease has constituted a natural experiment in how societies respond to disability, dependence, fear, and death. In this sense, the manner in which a society responds reveals its most fundamental cultural, social, and moral values” (414-415). Indeed, policing sexuality has long been a mechanism for exercising power (Foucault 1978) and AIDS is no exception to this rule, given its association with sexuality and the moralism often attached to it as a result. These morals are apparent in the very metaphors used to describe AIDS (Sontag 1989) and in the ways that people most affected by HIV and AIDS have been turned into scapegoats, which is a common social response in cases of moral uncertainty (Schepers-Hughes 1993). Brandt (1988) points to “our relative lack of sophistication in comparing risks” (427) to explain why the AIDS epidemic has appeared so menacing in the
U.S., and why certain people seem to pose a more immediate risk than others.¹ So, defining HIV/AIDS as an “epidemic” is especially meaningful for the ways in which it encapsulates and “dramatizes” some of society’s biggest fears around sex, drugs, and inequality.

**Ending an Epidemic: Why, How, and What It Means**

For approximately the past 100 years, public health professionals have launched various campaigns to eradicate life-threatening diseases such as smallpox (Fenner 1982), polio (Aylward and Yamada 2011), malaria (Gabaldon 1969), and yaws (Hopkins 1985). Of these, only the smallpox initiative has truly been successful (Bazin 2000). According to former CDC virologist Walter R. Dowdle, disease “eradication” or “elimination” have been defined as:

- **Control:** The reduction of disease incidence, prevalence, morbidity or mortality to a locally acceptable level as a result of deliberate efforts; continued intervention measures are required to maintain the reduction. Example: diarrhoeal diseases.
- **Elimination of disease:** Reduction to zero of the incidence of a specified disease in a defined geographical area as a result of deliberate efforts; continued intervention measures are required. Example: neonatal tetanus.
- **Elimination of infections:** Reduction to zero of the incidence of infection caused by a specific agent in a defined geographical area as a result of deliberate efforts; continued measures to prevent re-establishment of transmission are required. Example: measles, poliomyelitis.
- **Eradication:** Permanent reduction to zero of the worldwide incidence of infection caused by a specific agent as a result of deliberate efforts; intervention measures are no longer needed. Example: smallpox.
- **Extinction:** The specific infectious agent no longer exists in nature or in the laboratory. Example: none. (1998, 23)

However, while it may be possible to eradicate or eliminate a particular disease, not all diseases are good candidates for resource-constrained public health initiatives. The 1997 Dahlem Workshop on the Eradication of Infectious Diseases established several criteria to determine whether a disease is technically “eradicable” by public health standards. These criteria include

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¹ An assertion that feels especially poignant almost 30 years later when the U.S. is spending huge sums of money on the “War on Terror” while still upholding domestic gun ownership rights in the wake of an “epidemic” of mass shootings across the country.
the biological and technical feasibility of eradication (whether the disease lives and spreads in such a way that it can be contained and eradicated, as well as whether or not effective and feasible interventions exist to curtail it), the costs and benefits associated with eradicating the disease (this includes both direct cost savings as well as coincidental benefits, such as improved immunization and surveillance systems), and whether the social and political climate are conducive to eradication (such as, whether there is political commitment and sufficient resources) (Aylward et al. 2000).

According to New York’s Blueprint to End the AIDS Epidemic, “The end of the AIDS epidemic in New York State will occur when the total number of new HIV infections has fallen below the number of HIV-related deaths” (New York State Department of Health 2015, 5). Officially, the campaign sets this point of “bending the curve” (of new HIV infections against HIV-related deaths) at less than 750 new infections per year, although this number seems to be more of a general estimate than a hard turning point. One official with the New York State Department of Health’s AIDS Institute says they consulted with a prominent HIV prevention researcher to discuss “what would be some tipping points” and the goal of 750 seemed like a “fair, objective” assessment of what is “attainable” without a vaccine or a cure. Meanwhile, one of the activists who has been heavily involved in data-related work for Ending the Epidemic says, “We had a lot of discussions about the mathematical definition of eliminating an epidemic, which means getting the reproductive number to be below one. And their number is fairly arbitrary. They basically are saying if we reduce it 75%, that’s below epidemic. That’s endemic levels.”

In fact, a copy of Dowdle’s paper was distributed to attendees at one of the earliest Ending the Epidemic planning meetings and there was debate about the difference between
disease eradication versus elimination versus control at a meeting held to discuss preliminary metrics for the campaign in October 2014. So, it would appear that organizers were working directly from these exact definitions of disease eradication verses elimination. And ultimately, New York State’s definition of the end of the epidemic falls in line with Dowdle’s definition of disease “elimination” while also taking advantage of the somewhat vague public health definition of an epidemic to estimate its own numeric end point.

While the potential to “eliminate” HIV/AIDS might raise questions of feasibility and cost-effectiveness from public health practitioners, referring back to Rosenberg (1989) and Brandt (1988) above, eliminating or ending an epidemic has a different kind of meaning from a social perspective. If an epidemic both encapsulates and dramatizes society’s fears, perhaps the prospect of ending an epidemic indicates that these fears are waning. Certainly homosexuality (long associated with HIV/AIDS) has become much more socially acceptable in the U.S. since the 1980s, with the Supreme Court recently ruling that “same-sex” marriage is a right guaranteed by the Constitution (Liptak 2015). But for those who have been engaged in AIDS activism for a long time, the end of the epidemic means something much more personal. As Joan, a member of the Ending the Epidemic Task Force, told me in an interview:

I lost a lot of beautiful, young, black gay men when I first started doing this work in ’89. And, you know, these were young men who got a diagnosis and then they were in St. Vincent’s [hospital] dying. And these were men who were telling me, “You’ve gotta do this work. You’re our sister. You’ve gotta do this work until it’s over.” And so it’s also a very emotional thing to be part of the end of AIDS Task Force, because I’ve continued to do HIV…for years. And the idea that it’s over and that my, not my obligation, but my promise, my pledge is coming into being is bizarre. Because I didn’t think it would. Ever.

Like the activists I quoted at the beginning of this chapter who recall those they have lost to HIV/AIDS when doing their work, Joan suggests that ending the epidemic is the fulfillment of a
promise to those colleagues, friends, and lovers. Maybe the end of the epidemic means that Joan and other long-time activists in the field really have done the work “until it’s over.”

Ending the Epidemic in Context: Why Now?

When describing how Ending the Epidemic began, many people I interviewed referred to the “story” of two of ACT UP’s original members, Charles King and Mark Harrington, who hatched a preliminary plan to end AIDS in New York State while sharing a jail cell after their arrest at a 2012 protest in Washington, D.C.\(^2\) In most cases the story is told as though the two activists were suddenly, almost miraculously, inspired to end AIDS in New York. As Charles said to me during an interview, “The legendary story that you’ve heard so many times, that’s where Mark and I had the conversation in jail.”

And yet, this “legendary story” belies an entire history and structure behind Ending the Epidemic. Structural factors at the international, national, and state levels both inspired and laid the groundwork for Ending the Epidemic. On an international scale, then-Secretary of State Hillary Clinton had proposed a global plan for an “AIDS-free generation” and a 2012 article from *The Nation* notes that “Talk of ending the epidemic dominates the [International AIDS] conference this year…” (Gira Grant 2012). But efforts like AIDS-Free World, founded in 2007 by former UN Special for HIV/AIDS in Africa Stephen Lewis, and the U.S.-based Campaign to End AIDS, founded in 2005 with involvement from Charles King, have been around much longer. Indeed, the world began talking about the end of AIDS as early as the mid-1990s, when a new class of antiretroviral drugs (protease inhibitors) showed real promise in treating HIV for the first time (Sullivan 1996).

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\(^2\) Indeed, the International AIDS Society’s bi-annual International AIDS Conference was held in Washington, D.C. in July 2012, and stories from *The Huffington Post* (Carter 2012) and *The Washington Post* (Evans and Constable 2012) confirm both protests and about a dozen arrests at the International AIDS Conference that year.
Equally as important as the number of efforts launching across the globe to end AIDS, the knowledge base around using pharmaceuticals to prevent HIV started to grow substantially in 2010. That year, the iPrex trial showed that some of the same drugs used to treat HIV also could be used to prevent infection among men who have sex with men (Grant et al. 2010). These results have since been corroborated among people who use drugs and heterosexual couples (Kachit et al. 2013; Baeten et al. 2012), and prompted the U.S. Federal Drug Administration to approve the HIV treatment drug Truvada for use as pre-exposure prophylaxis (PrEP) in 2012. Following shortly on the heels of the iPrex trial, the results of the HPTN 052 trial to investigate the effects of early antiretroviral therapy treatment on HIV transmission in sero-discordant couples (in which one partner is HIV-positive and the other is HIV-negative) found that early treatment was highly effective in protecting HIV-negative partners from contracting the virus (Cohen et al. 2011). Taken together, the findings on PrEP and treatment as prevention (TasP) have ushered in a new era of HIV prevention that no longer relies mainly on condoms, which people tend to use inconsistently due to structural barriers (e.g. Shannon et al. 2009) or simply out of personal preference and “condom fatigue” (Rowniak 2009). Other methods that have been introduced along the way, such as voluntary medical male circumcision, have shown some effectiveness (Bailey et al. 2007), but also have proven controversial due to the minimal effects they show for preventing HIV in women (Mantell et al. 2013). Meanwhile, the female condom has proven effective in preventing HIV transmission (CDC 1993; Gollub and Stein 1993), but has never been widely produced or used due to unequal gender relations that have limited their acceptability and accessibility (Mantell et al. 2006). Other prevention options specifically for women, such as a vaginal microbicide, also have stalled for similar reasons (Power 2015).
As new research findings around PrEP and TasP were being released and the world was engaging more and more in conversations around ending AIDS, under President Barack Obama the U.S. Office of National AIDS Policy (ONAP) released a National HIV/AIDS Strategy in 2010 that aimed to reduce new HIV infections, increase access to care and improve health outcomes for people living with HIV, and reduce HIV-related health disparities by 2015. This was the country’s first comprehensive and coordinated plan around HIV/AIDS. While the plan was criticized among those working in the field for not paying sufficient attention to women’s needs (Positive Women’s Network 2010) and to the needs of people of color in general (National Black Leadership Commission on AIDS 2010), it was particularly notable given the relative lack of attention to HIV/AIDS in the U.S. under previous President George W. Bush. While the President’s Emergency Plan for AIDS Relief (PEPFAR) is lauded as Bush’s greatest (some would say his only positive) legacy, this plan directed large sums of money toward addressing HIV/AIDS in Africa while funding for proven HIV prevention strategies (e.g. comprehensive sex education) was cut in the U.S. As Gregorio Millett, a senior policy at ONAP under President Obama, recently said in an interview with The New York Times:

During the Bush years, the administration dropped all pretense that they cared about AIDS in this country… The White House said H.I.V. is only a problem in sub-Saharan Africa, and that message filtered down to the public. Though the Bush administration did wonderful work in combating H.I.V. globally, the havoc that it wreaked on the domestic epidemic has been long-lasting. (Villarosa 2017)

Indeed, several activists I spoke with noted that much attention among the general public and within funding circles for HIV/AIDS shifted to sub-Saharan Africa around this time to the detriment of the epidemic at home. Not only did PEPFAR start directing resources toward the region, but the Bill and Melinda Gates Foundation, the largest private funder in the U.S., began funding HIV/AIDS in 1998 with the bulk of their money directed internationally (Funders
Concerned About AIDS 2002). Indeed, even gay rights organizations like the Human Rights Campaign, which initially supported work around HIV/AIDS, began to turn to advocacy around same-sex marriage. As Charles King said to me in an interview, starting in the mid-1990s, “in the public mind, I think AIDS…in Africa was seen as a big crisis, but AIDS in the United States was not.” However, I can’t help but wonder if this shift is also related to the idea that AIDS was under control among the white men initially infected due to the availability of antiretroviral medications (ARVs) beginning in the mid-1990s. In any case, when ONAP released the 2010 National HIV/AIDS Strategy, AIDS advocates had been waiting for a long time.

In addition to releasing the national strategy, the Obama administration had also set the stage for Ending the Epidemic by passing the Affordable Care Act, which was meant to expand healthcare access across the country, including provisions for individual states to expand access to Medicaid. Since poverty is one of the greatest risk factors associated with HIV infection and deaths due to AIDS-related complications (Farmer 2006; Singer 1994), expanded Medicaid access is particularly important for people living with and at risk of contracting HIV. As Mark Harrington, one of the founding Ending the Epidemic activists noted, “…the advent of Obamacare, as imperfect as it is, provided an opportunity to look at the U.S. epidemic in a different way.”

Against this relatively hopeful backdrop both globally and domestically, New York State already had good reason to be optimistic about its own efforts. On the one hand, a healthy dose of exceptionalism tends to give New Yorkers the confidence that they can achieve what others cannot. As one Ending the Epidemic Task Force member said to me, “So goes New York, so goes the rest of the country.” In some respects, New York has good reason to be confident. While New York City was one of the sites hardest hit by HIV/AIDS in the beginning, the
The epidemic is now growing disproportionately in the South while new diagnoses have been steadily declining in New York for years (New York State Department of Health AIDS Institute 2016; U.S. Centers for Disease Control and Prevention 2016). Still, with a rate of 18.6 new HIV diagnoses per 100,000 population in 2015, New York only falls just behind some of these southern states (e.g. Texas and Mississippi with rates of 20.1 and 20.6 respectively) and trails California (with a rate of 14.5), another state hit early and hard by HIV. Rates of infection among Black/African-American populations are also quite high in New York, which had the country’s second-highest prevalence rate in this population in 2015 (falling only behind the District of Columbia) (U.S. Centers for Disease Control and Prevention 2016). However, New York State still follows established trends in which incidence and prevalence rates are higher in major metropolitan areas (New York City) than in non-metropolitan areas (New York State Department of Health AIDS Institute 2015). This is in contrast to some parts of the country (most notably, Indiana (Paquette 2015)), where there has been an unprecedented spike in HIV incidence outside of cities due to an emerging “epidemic” of opioid addiction (Runyon 2017; U.S. Department of Health and Human Services 2016; Keyes et al. 2014).

Despite still relatively high rates of both HIV incidence and prevalence in New York, bringing new infections down so dramatically has been no small feat. Both in interviews and in public meetings, those close to the campaign consistently recognize a history of successes in curbing New York’s epidemic, such as the virtual eradication of perinatal transmission (in which a fetus contracts HIV from the mother in utero) (Cutler 2015) and drastic reductions in the overall number of new HIV transmissions per year since the 1990s (New York State Department of Health AIDS Institute 2013). These successes suggest that New York already has a proven track record of curbing its own epidemic, which is likely due, at least in part, to the fact that the
state provides one of the most generous HIV/AIDS service packages in the country. This package includes: the state-sponsored AIDS Drug Assistance Program (ADAP); ADAP Plus to cover primary care visits; and HIV home care services. More recently, state government also elected to expand Medicaid and the Medicaid system is being re-structured into a system of value-based payment, which is meant to reward medical service providers for patient outcomes rather than paying for individual services. In addition, New York City offers housing, nutrition, medical, and transportation support through its HIV/AIDS Services Administration (HASA). New York State also achieved a big gain for housing rights when the “30% rent cap” policy passed in 2014, limiting rental payments for those receiving HASA services to 30% of their income, and as a result greatly reducing the risk that these people will become homeless. Homelessness is closely linked with HIV/AIDS in terms of putting people at risk for contracting the virus, as well as further jeopardizing their health if they are HIV-positive (Shubert and Bernstine 2007).

Interestingly enough, the 30% rent cap may have passed as a result of EtE efforts even before the campaign officially launched. Once Ending the Epidemic talks began with Governor Cuomo’s office, the director of the New York State Department of Health’s AIDS Institute, Dan O’Connell, reports that he was asked for recommendations for the governor’s budget, so “I put it in there,” saying, “Well, listen, these are really big things that we could do that would show that we’re for real.” Dan pointed out that it used to be difficult to get this kind of legislation through and that activists had been advocating for the 30% rent cap for 20 years. This time, though, he thinks both the senate and the assembly were able to pass this measure because they had “the unanimous approval of the community” and ultimately “the community was rapturous over the 30%...”
AIDS Activism & New York

The ACT UP Origins

So, domestic and state-level politics set the stage for Ending the Epidemic in New York, but the state also was primed by its history of activism. New York has been one of the main centers of both activism and state government action around AIDS in the U.S. virtually since the beginning. Due to its status as a major cosmopolitan center with a thriving gay scene, and particularly as a hub through which millions of people passed for both work and play on a regular basis, New York City was one of the cities most affected by HIV/AIDS early on. At the same time, the City had a long history of activism ranging from labor rights in the form of organizing around events like the Triangle Shirtwaist Factory fire of 1911 (McEvoy 1995) to neighborhood organizing against gentrification, as in Greenpoint-Williamsburg in the late 1970s (Susser 2012). More directly related to HIV/AIDS organizing, activism around gay rights, as seen in the 1969 Stonewall riots (Carter 2010; Poindexter 1997), and women’s rights (Taylor 1989), was partly inspired by the “Free Love” movement of the 1960s and ‘70s (Highleyman 2002). Indeed, HIV/AIDS was sometimes considered, “the proverbial wrench thrown by fate/chance/god/the cosmos (pick your ideology) into the delicious sexual revolution” (Young 1991), and threads from these earlier movements certainly made their way into AIDS activism; populations that had fought so long to have their sex lives recognized as legitimate now faced a threat not only to this legitimacy but to their safety. Indeed, contemporary AIDS activism still draws on sex-positive themes and activist meetings are often peppered with sexual references, a method of claiming and legitimizing sexuality.

In short, New York was ripe for AIDS activism. It should come as no surprise, then, that the most famous and most prolific AIDS activist group in the country, the AIDS Coalition to
Unleash Power (ACT UP), was founded in 1987 at New York City’s Lesbian and Gay Community Services Center (now the Lesbian, Gay, Bisexual, and Transgender Community Center). From its inception, ACT UP / NY garnered hundreds, sometimes thousands, of attendees at its weekly meetings, and chapters quickly spread across the globe. While the group ultimately espoused the idea that “healthcare is a human right,” it focused much of its energy on “direct action” tactics to speed up the development of and access to HIV treatment (Gould 2009).

Some of ACT UP’s most notable and dramatic demonstrations include a day-long shutdown of the Food and Drug Administration (FDA) in 1988 to protest the FDA’s long drug approval processes, and “storming” the National Institutes of Health in 1990. Video footage of the FDA protest shows masses of people gathered in front of the FDA building screaming, “Release the drugs now!,” “Get to work!” and “Seize control!” while ACT UP member Peter Staley climbs a low-level roof and unfurls a banner reading “SILENCE = DEATH” (one of ACT UP’s slogans) (France 2012). Gould (2002) suggests that this kind of event reinforces the power of emotion that ACT UP harnessed, encouraging activists to focus on their rage and direct it toward decision-making institutions. Further, the dramatic aspect of ACT UP protests seems to coincide with Rosenberg’s (1989) assertion that epidemics are themselves dramas.

Ultimately ACT UP’s tactics proved relatively successful, because they were accompanied by deliberate efforts among AIDS activists to become conversant in the language of science and to engage directly with policy makers. According to Epstein (1995), AIDS activists in the early 1990s were notable for their ability to gain credibility as lay experts and, in turn, to influence shifts in policy around AIDS drug testing that opened clinical trials to more participants and sped up delivery timelines. However, by the time a highly effective class of drugs called “protease inhibitors” was released in 1996, ACT UP had largely fallen apart (with
two of its major sub-committees, one on treatment and data, and the other on housing issues, becoming separate organizations; the Treatment Action Group (TAG), led by Mark Harrington, and Housing Works, led by Charles King), as had much large-scale AIDS activism in the U.S.

Yet, the narrative of white gay male activism, and particularly ACT UP’s work, is incredibly strong in the literature on AIDS activism. To be sure, ACT UP was extremely influential in the early days of the epidemic, but its dominance of the literature is striking. This, too, may be related to the status that many of ACT UP’s members already enjoyed as educated white men, which gave them greater leverage to act as credible voices in multiple venues, and also to achieve professional status as directors of organizations like Gay Men’s Health Crisis (GMHC), Housing Works, and the Treatment Action Group. Not only have numerous pieces been written about the organization itself and its activist tactics (e.g. Dubrow, Knopp & Brown 2015; Offen, Smith & Malone 2003), but in turn many ACT UP members have contributed to the archive by using their personal experiences as fodder for books, articles, and films (see for example: Gonsalves and Staley 2014; Strub 2014; Killen, Harrington, and Fauci 2012; Bordowitz 2004; Sawyer 2002).

*The Many Faces of AIDS Activism*

**Women and AIDS**

While gay white men were long considered the “face” of HIV/AIDS in the U.S. and have dominated this literature in many ways, organizing by and for women and people of color has been pivotal to the field, if often overlooked. Within ACT UP itself, sub-committees and caucuses formed early on to address the concerns of multiple populations, such as the Majority Action Committee (focusing on people of color), the Latino Caucus (with membership restricted only to those with a Latin@ background), and the Women’s Caucus. Contrary to what I had
heard about and read, when I spoke with a former member of the Women’s Caucus and the ACT UP Women New York and AIDS Book Group, and asked what she thought it was like to be a woman in ACT UP, she responded “The question doesn’t make sense to me.” Miranda went on, “It’s a stereotype that it was a group that was dominated by gay, white men, but the lesbians were the…brains of the operation.” Having come out of the Women’s Health movement and queer knowledge-building initiatives like the Lesbian Herstory Archives, Miranda said, “Lesbians were accustomed to the notion that if we were gonna create spaces that were gonna promote our health and safety…we had to build them ourselves.” Indeed, the Women’s Health movement (Morgen 2002; Boston Women’s Health Collective 1976) encouraged women to take ownership of their own health through personal education and questioning the medical establishment, and has been credited as one of the precursors to AIDS activism (Epstein 1995; Corea 1993).

In addition to organizing their own direct actions, such as a protest at Shea Stadium where they held up banners declaring “No Glove, No Love,” part of the ACT UP Women’s Caucus also spawned the ACT UP New York Women and AIDS Book Group. This group produced the book Women, AIDS and Activism (ACT UP NY Women and AIDS Book Group 1999), which was originally published in 1990 and addresses the biology of HIV in women, perspectives on race, gender, and HIV, and the relationship between HIV and women’s sexual and reproductive health. Miranda told me the book was a “big hit” and at two workshops the group organized around the book, “I just remember the room being full.” The book remains highly influential to this day and Miranda suggested that many of the original women of ACT UP have contributed to the movement precisely through the practice of archive and documentary. Women like Sarah Schulman, who produced the documentary United in Anger: A History of
ACT UP, and Jean Carlomusto, who produced the HBO documentary, Larry Kramer: In Love and Anger, were part of ACT UP.

Still, Miranda recognized that ACT UP meetings were divided into a left side and a right side of the room. On the right side were the members who focused on data and access to treatment. Most of the women sat on the left side, where they were looking at issues in the context of race, class, economics, and larger social structures and education; “We weren’t as dead seriously focused on getting a seat at the table at the CDC.” When I pointed out that this kind of work seemed to garner more attention Miranda agreed, but when she reflected later on the difference in publicity some of the ACT UP men received versus the women, she joked, “Why does Larry Kramer get all this focus and Maxine Wolfe is pretty much unknown?...Maxine doesn’t really do an interview and Larry, you cannot take a microphone out of his mouth.” While Miranda seems to be pointing to a personality difference here, I can’t help but think that men are generally encouraged to speak out in any situation while women often don’t receive the same kind of encouragement.

Beyond ACT UP, women have organized around such issues as promoting women-controlled prevention methods like the female condom (e.g. Gollub and Stein 1993). Indeed, I remember attending the 2006 International AIDS Conference in Toronto, where we held a women’s rally featuring a piece of art made entirely out of female condoms spelling the word “Survival” by the South African artist Fiona Kirkwood. The female condom never received much uptake, but ongoing advocacy around a microbicide (an intra-vaginal gel that would prevent HIV transmission) has recently seen some progress. Originally proven to be about 40% effective in preventing HIV transmission (Karim et al. 2010), follow-up studies using faulty
research designs that didn’t account for the realities of women’s daily lives have resulted in a
dearth of evidence around the gel’s efficacy (e.g. Rees et al. 2015).

Following larger trends in the field, much of the more recent activism around women and
HIV/AIDS work has tended to have an international focus, such as the microbicide trials in
southern Africa. Like much of the activist work around women and AIDS in the U.S. (e.g.
service providers like Iris House in Harlem that caters to women and Sister Love in Atlanta,
which was founded by one of the contributors to Women, AIDS and Activism, and engages with
HIV at the intersection with reproductive justice), this work tends to focus on the issues and
needs of women of color, who are disproportionately affected by the epidemic worldwide.
However, it is telling that Health GAP (Global Acces Project), an international organization that
advocates for access to HIV treatment, includes a particular focus on women grassroots
organizers in its “AIDS-Free Generation” in Kenya campaign (http://www.healthgap.org/kenya),
while women barely receive mention in the larger field of HIV/AIDS advocacy in the U.S., even
when women activists are at the forefront. For example, a recent New York Times Magazine
piece on the South’s rapidly growing HIV epidemic, written by a woman of color, only mentions
the word “woman” twice; first to note that initially there was a “disturbing increase” in HIV
among black women and second to point to homophobia in the church, which defines marriage
as being only between “one man and one woman” (Villarosa 2017). What happened to the
women of color who were so affected by HIV early on? We don’t know, because the article only
focuses on men who have sex with men (MSM) of color. As Miranda pointed out, women have
been great archivists for AIDS activism, and yet in the U.S. they don’t seem to be archiving
themselves.

AIDS and Activists of Color
In June 2017, ACT UP held a “Hidden Histories” conference to highlight the contributions of some of the group’s caucuses, such as the Women’s Caucus, the Latino Caucus, and the Majority Action Committee. At the conference, speakers catalogued the achievements of these various groups, such as educational events organized by the Majority Action Committee in communities of color and their work with outside partners to host conferences focusing on HIV/AIDS among people of color in both New York and Chicago, while the Latino Caucus conducted similar outreach among Latin@ communities and conducted the first Spanish-language AIDS education session in New York City. Indeed, when I spoke with a couple of men who are part of the Latino Caucus, they noted that the Caucus helped found a chapter of ACT UP in San Juan, Puerto Rico, and they also have worked with another chapter of ACT UP in Argentina.

However, one of the activists I spoke with, Hector, told me that he only ever attended the Latino Caucus meetings and never a full ACT UP meeting, and he was not the only one who did this. While Carlos attended both Latino Caucus and regular ACT UP meetings, unlike Miranda, he spoke at length about inequalities he perceived along racial and ethnic lines within the group. In some respects, Carlos considered these divisions to be productive, saying, “ACT UP was founded mostly by a group of people that had never experienced disadvantage and they were shocked” by the experiences of their colleagues. However, Carlos noted that it was difficult and intimidating for some members of the Latino Caucus to participate in ACT UP because there were some “very powerful voices in ACT UP…[that] dominated the conversations. And it was sometimes a little bit hard…when you have issues like language or accent.” Interestingly enough, Carlos postulated that the issue of language was not only a product of speaking English versus Spanish, but also of education and class: “Sometimes it’s very challenging to mix groups
with very different educational levels…it can be very scary to be around people that can quote, I
don’t know, whoever.” And speaking of ACT UP members with less education, “I find our
meetings probably are too challenging for people that come from that background.” Indeed,
Carlos noted that much of ACT UP’s new membership seems to be coming from college-
educated young people who are learning about the organization’s work in their classes, although
there has been a little more diversity in ACT UP’s Youth Caucus, which members like Carlos
recruited for specifically at an organization that caters to LGBT homeless youth.

Still, Carlos told me that he knows of at least one person who left ACT UP to become
more involved with Voices of Community Activists and Leaders (VOCAL-NY), an organization
that specifically works on social justice issues related to HIV/AIDS, housing, drug use, and mass
incarceration. As Carlos noted, “If you look at the membership of VOCAL, it’s 90% African-
American and poor… in many ways what is happening is that some of those people feel more
comfortable doing their work through VOCAL than through ACT UP.” Indeed, VOCAL’s
membership seems to reflect the changing face of the epidemic in ways that ACT UP does not
and this is reflected in VOCAL’s ability to mobilize large groups, which one activist suggested
to me they are better able to do than ACT UP. VOCAL seems to attract so many members not
just because certain people feel more “comfortable” there than at an ACT UP meeting, but
because they focus on issues particular to certain populations highly affected by HIV/AIDS.
Similarly, other prominent activist organizations in New York include the Latino Commission on
AIDS, which focuses on issues of particular interest to Latin@ communities, such as
immigration, while also promoting awareness and acceptance of LGBT issues, and the National
Black Leadership Commission on AIDS (NBLCA), which runs campaigns across the country to
educate black leaders about issues related to HIV/AIDS so that they can address these issues in
their own communities. There also are a number of health centers in New York City that specialize in HIV prevention, treatment, and care, and offer free or low-cost healthcare catering directly to populations of color, such as Apicha Community Health Center, which specializes in working with Asians and Pacific Islanders, and Harlem United, which is meant to serve Harlem’s majority-Black population. In addition to clinics, these organizations generally have advocacy arms as well that focus on issues relevant to the community they serve. For example, Harlem United offers treatment for substance users and supportive housing. These kinds of organizations appeal to diverse populations by positioning themselves directly in communities of color and addressing the intersectional health needs of that community.

Theorizing Inequalities in AIDS Activism

Gould (2002) attributes ACT UP’s decline to a change in context by the mid-1990s, in which the policy environment had shifted and the movement became more mainstream, but she also notes the increasing factionalization in the movement at this time, particularly along lines of gender, race, ethnicity, and class. Indeed, AIDS activism was founded on identity politics, drawing from gay and lesbian civil rights activism (Hodge 2000) as well as the women’s health movement (Corea 1993). Gamson (1989) suggests that, in some sense, groups like ACT UP worked to “normalize” gay identity by re-appropriating stigmatized images and messages, but the pitfalls of identity politics are many. First, organizing around an identity in protest ultimately reifies that very identity, while also reinforcing negative associations that go along with it. If, for example, a gay identity exists, then so can a “gay disease” such as AIDS (Epstein 1987, 19).

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3 This is a concept that has long been fraught within queer communities. As Warner (1999) points out, for example, a semblance of heteronormativity should not be the goal for people who identify as queer, but rather the social normalization of a range of sexual lives.
Further, identities can create factions within a movement, and in some cases rely on race, ethnicity, class, and gender inequalities for their success. As Gamson writes:

It is important to notice that ACT UP’s identity-oriented actions often revolve around boundary-crossing and label disruption. These are strategies for which these mostly white, middle-class gay people are particularly equipped, largely because their stigma is often invisible, unlike, for example, the stigmatized person of color. They can draw on a knowledge of mainstream culture born of participation rather than exclusion and, thus, a knowledge of how to disrupt it using its own vocabulary. (1989, 362)

Indeed, Epstein (1995) also recognizes that gains around the politics of knowledge in AIDS activism were partly attributable to the fact that many activists were gay white men.

Perhaps more importantly, though, when one identity becomes the “face” of a movement (as described earlier in the chapter), this identity tends to displace or subsume others in the name of advancing the cause. ACT UP, for example, has received accusations of racism in the past. As Gould (2012) explains it:

Racism was particularly pronounced in ACT UP’s internal conflicts. Disagreements…intensified and engulfed many ACT UP chapters in the early 1990s in large part because there seemed no end to the accelerating epidemic, many participants felt increasingly desperate, and a sense emerged that our activism might not be able to interrupt the dying. In that context, a scarcity mentality took hold: activism regarding issues of concern to one groups of people with AIDS (PWAs) came to be seen as diverting activist energy and resources from other PWAs. (56)

Gould’s statement feels a lot like suggestions that black women have had to subsume their interests as women for the greater good of coming together under the banner of race (Davis 1981a), which ultimately proved challenging for feminist organizing (hooks 1984). Indeed, this “scarcity mentality” seemed to take hold with regard to women as well. Despite the existence of a sizable contingency of women in ACT UP⁴ and actions staged by the group specifically on behalf of women’s rights (Shotwell 2014), women have long been underrepresented in the

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⁴ Partly represented by the ACT UP/NY Women & AIDS Book Group (see ACT UP NY Women & AIDS Book Group 1999).
movement both in terms of their physical presence in groups like ACT UP and in attention to their concerns. This underrepresentation, on top of gendered power imbalances in society at large, resulted in delays developing guidelines for diagnosing women with HIV, and consequently including women in clinical trials and giving them access to treatment (Susser 2009; Elbaz 2003; Patton 1994).

Race and gender imbalances in AIDS organizing seem to be reflected in the academic literature as well. As McAdam (1992) has pointed out, social movements literature has tended to focus on the distinction between activists versus non-activists, as opposed to examining differences among activists within the same movement. In his study of civil rights activism during the “Freedom Summer” of 1964 in Mississippi, McAdam notes that women involved in the movement reported very different experiences from their male colleagues in terms of the kinds of work they were assigned (stereotypically gendered clerical and classroom work) and the double standards they faced in their personal lives (e.g. norms around dating). Others (e.g. Fendrich 1977) have similarly shown how civil rights activism was different for black versus white activists.

McAdam (1986) and McAdam and Paulsen (1993) postulate that participation in activist movements is largely determined by “microstructural” factors that both expose potential activists to the movement and ultimately pull them in. Building on Stryker and Serpe’s (1982) theory of identity “salience,” McAdam and Paulsen suggest that social movement recruitment depends on the salience of identity invoked by the movement and how much support (or not) a potential participant feels from people who sustain or reinforce that identity for them. In particular, a potential participant should not feel strong opposition from family members, friends, etc. who support other kinds of salient identities. However, while these theories begin to account for
differential experiences among activists, they suffer from two harmful assumptions: 1) they still assume that social activist movements have one point of focus rather than being themselves multi-dimensional like their members; 2) they do not account for larger structural factors (beyond “microstructures”) that could hinder or encourage activist participation.

As Stockdill (2001) points out in his analysis of AIDS activism among people of color, most work on social activism has focused on “unidimensional frames – frames that seek to transform consciousness and society on one level” (205) rather than looking at intersecting social inequalities that have a “multiplicative effect” when experienced simultaneously (207). Indeed, this concept of “intersectionality” has been particularly pronounced in works by academics and activists of color who have themselves experienced the “multiplicative” effects of being, for example, both homosexual and a racial or ethnic minority (Trujillo 1991; Lorde 1984; Baldwin 1955) and from black feminist scholars (Collins 1998; King 1988). In many cases, feminist scholars of various racial and ethnic backgrounds have particularly pointed to the importance of using an intersectional lens in the context of the broader scheme of global capitalism, which creates inequalities on multiple fronts (Susser 2009; Brodkin 2000; Davis 1981b).

Returning to the theme of health and inequality we know that, while men of color do not have to contend with the gender power imbalances women face, they similarly face the structural constraints of race and often class, which tend to be associated with HIV risk factors such as homelessness and drug use (Strathdee and Stockman 2010; Rhodes et al. 2005). Similarly, a combination of racism, homophobia, and financial hardship can adversely affect all men of color who have sex with other men (Ayala et al. 2012), and a lack of acceptance of homosexuality in many communities encourages black men to be on the “down low” with their sexuality, which puts them at greater risk for contracting HIV (Bond et al. 2009; Lichtenstein 2000). Among
Latino men, multiple ideologies of risk (Diaz and Ayala 1999), as well as ideologies of masculinity and uneven access to healthcare may also influence the likelihood of contracting HIV (Rhodes et al. 2007). And migrant labor patterns have contributed to increasing rates of heterosexual transmission from men who temporarily migrate to the U.S. from Mexico and then transmit the virus to their wives upon returning home (Hirsch et al. 2002).

Gendered inequalities are particularly relevant for the health of women of color, who are far more likely to contract HIV than their white counterparts (Mueller 1998; Land 1994). In an analysis of her own work on the Harlem Birth Right Project, Mullings (2005) points to the importance of intersectionality in understanding why people of color, and especially women, experience poor health outcomes. As she writes:

The intersectional lens refocuses our perspective on health and illness in several important ways. It invites us to understand race, class, and gender as relational concepts: not as attributes of people of color, the dispossessed, or women but as historically created relationships of differential distribution of resources, privilege, and power, of advantage and disadvantage. Attention to the historical and contemporary processes by which populations are sorted into hierarchical groups with different degrees of access to the resources of society shifts our analysis to racism rather than race, toward gender subordination as well as sex as biology, and to resource distribution as the larger context that constrains and enables what appears as voluntary lifestyle choices. The intersectional approach also requires that we interrogate the manner in which these axes of stratification intersect. It emphasizes the ways in which race, class, and gender are not additive but rather interlocking, interactive, and relational categories…(79-80)

In sum, Mullings poignantly writes, “While race may not be biological, racism has biological consequences” (87). The same could also be said for gender as we interrogate the relationship

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5 Other communities of color, such as Asian/Pacific Islanders and Native American/Alaska Natives, make up extremely small percentages of PLHA: approximately 1% and less than 1% respectively (U.S. Centers for Disease Control and Prevention 2008). This is partly why Asian/Pacific Islanders and Native American populations often are left out of the AIDS literature entirely. However, this may also have to do with conceptions of Asian-Americans as essentially “white” in terms of their educational levels and socioeconomic status (Omi 2008).

6 The Harlem Birth Right Project was an initiative to understand why black women tend to have poorer birth outcomes than women of other races despite being of similar socioeconomic status. This was an intensive ethnographic study conducted in Harlem from 1993 – 1997 that involved a large multidisciplinary team of researchers who conducted participant-observation and interviews with women in the neighborhood to learn about the constraints they face in their daily lives. For more information see Mullings 2005.
between social gender and biological sex that has long been taken for granted (Butler 1990). Further, Mullings’ quote above also is noteworthy for its reference to “choice.” As Mullings points out, choices that appear to be voluntary are in fact constrained by intersecting structural factors. This is a theme that comes up often in the anthropological literature on reproduction (e.g. Davis 2009; Colen 1995), which analyzes the ways in which gender and race circumscribe many kinds of reproductive choices and experiences. As Susser (2009) pointedly writes of the disproportionate affect HIV and AIDS have had on women worldwide, but which could be interpreted to encompass intersectionality and health more generally, “Clearly, we are watching the interplay of inequality in race, class, and gender reflected in the medical and health experience” (33).

Stockdill (2001) suggests that addressing intersectional oppression has been challenging for social movements like AIDS activism precisely because intersecting “isms” (racism, sexism, classism) often clash with each other. Even within one movement, “The existence of multiple interlocking oppressions creates the potential for the oppressed to act as the oppressor” (207). For example, gay black men may exert gender domination over black lesbians, or heterosexual people of color may act homophobic toward non-heterosexual peers. Indeed, researchers point to homophobia and classism as barriers to mobilization around HIV/AIDS in communities of color (Ramirez-Valles and Uris Brown 2003; Quimby and Friedman 1989), although more recent research suggests that some institutions historically associated with homophobic messaging, like black megachurches, are attempting to open up the conversation around AIDS and related stigma with parishioners (Barnes 2013; Beadle-Holder 2012).

For these reasons, Stockdill postulates that AIDS activism addressing intersecting oppressions must take a different approach than the direct action tactics used by prominent
groups like ACT UP. On the one hand, marching in the streets with its potential for arrest is far riskier for people of color than for white people (Alexander 2012; Stockdill 1996), but multidimensional oppositional consciousness must also be sensitive to raising awareness and galvanizing movement around all oppressions at the same time, which requires a nuanced approach. Stockdill found that this kind of activism often involved: constructive dialogue to challenge prejudices; empowerment initiatives to encourage people to advocate for themselves in multiple dimensions; community embeddedness to build trust for initiatives among people who have been historically oppressed; and the use of cultural traditions to make activist messages legible to different populations.

As Stockdill sums up, AIDS activism among people of color looks different than the picture we often see in the academic literature. He explains:

The difficulties of dealing with one-dimensional oppositional consciousness may partially explain the paucity of direct action AIDS activism in gay communities of color. Activists are so busy organizing to challenge intracommunity ‘isms,’ provide basic AIDS-related social services, and promote empowerment that they have less time than groups such as ACT UP to protest against dominant institutions. (2001: 235)

Instead, this type of activism gradually and quietly undermines elite power over time by raising awareness among people of color and giving them the tools to advocate for equity. As one of Stockdill’s interviewees, Roberta, said: “I think we want to be careful, ‘cause we don’t just want to say that when activism happens in communities of color, it’s more moderate, or it’s less militant, or it’s less confrontational, ‘cause that’s not always true – what’s confrontational might be different” (236).

In sum, a look back at the literature on AIDS activism begs the question of whether current activism, examined here in the form of the Ending the Epidemic campaign, indeed takes an intersectional approach. What kind of messaging does the campaign send out? Who makes
decisions and how are these decisions prioritized? To what extent do campaign organizers and participants struggle with intersecting oppressions and what comes of this struggle?

**Research Methods & Data Analysis**

**Data Collection**

This dissertation is based on 14 consecutive months of ethnographic fieldwork following government workers, HIV and AIDS service providers, academics, advocates, and “community” members involved in the Ending the Epidemic campaign. From the beginning, though, I offer the caveat that it is sometimes hard to define exactly which activities count as “Ending the Epidemic.” In some respects, as interviewees pointed out, EtE began long before the campaign itself was devised. This dissertation follows formal EtE-related events and activities that claim affiliation as much as possible. However, it also draws on activities and events organized by leading figures in the Task Force, since presumably they were invited to the Task Force because the work they already do every day is related to the overarching goals of the campaign. Further, as the campaign developed and grew, I wanted to get a sense of the directions it was moving in and its potential to really influence HIV/AIDS service providers and advocates throughout the state.

I began with the first meeting of the Ending the Epidemic Task Force in October 2014 and followed the campaign through to its implementation phase in December 2015. During this time, I attended formal meetings convened by the New York State Department of Health’s AIDS Institute, such as the monthly Ending the Epidemic “Task Force” meetings from October 2014 – January 2015, bi-monthly meetings of the Ending the Epidemic sub-committee of the NY State AIDS Advisory Council (beginning February 2015), and regional implementation meetings convened across the state from August – November 2015. I also attended numerous other
meetings convened by advocates and other community participants, such as the monthly NYers4PrEP Task Force, and meetings and demonstrations held by the AIDS Coalition to Unleash Power (ACT UP). Depending on the type of meeting or event I was attending, I would identify myself as a graduate student from CUNY working on my dissertation research. In smaller venues (e.g. the NYers4PrEP Task Force or ACT UP meetings), I would introduce myself this way and alert attendees that I was present to observe for my own research. However, most of the meetings and events organized by the AIDS Institute were quite large and open to the public, so I did not identify myself as a researcher in these venues.

In most cases I was treated as a researcher supporting the cause, something of an insider with an outsider perspective, which I suspect came from my work with a program run by the New York State Department of Health’s AIDS Institute (AI). From March 2014 – July 2016 I worked as a researcher on the qualitative evaluation of a program called NY Connects. NY Connects is meant to bring AIDS service providers together in regional groups throughout the state to work on quality improvement and to collaborate on innovative quality improvement projects. In the EtE implementation phase, NY Connects ultimately was identified as one of the venues through which campaign work would be carried out.

As one of two members on the NY Connects qualitative evaluation team and the main field researcher, I regularly attended and observed regional provider meetings and events, conducted interviews with both providers and with AIDS Institute staff and consultants running the project, and conducted a series of regional focus group discussions with providers. In short, through my work with NY Connects I became known to a number of AI staff, including a couple of staff at the senior level, and these staff members are to be credited with helping me both gain access to meetings and also to getting my project proposal through the AIDS Institute’s own
internal review board. Since I attended so many EtE-related events, I eventually became well known to the AIDS Institute staff in charge of Ending the Epidemic as well, leading one of them to joke that if she had to miss a meeting I could always fill in for her. The support I received for my work from these staff members opened many doors that otherwise might have been closed to me and their collegiality made the research process much nicer overall.

Insofar as my research sites were scattered throughout New York State, this project constitutes what Marcus (1995a) calls “multi-sited ethnography” in the most literal sense of the term. However, multi-sited ethnography is not only about the physical location of research sites, but about their metaphorical location as well. As Gupta and Ferguson (1992) point out, geographical location doesn’t necessarily create the most meaningful boundaries for cultural phenomena. In this respect, this research also was multi-sited due to the different types of meetings and events I attended, as well as the related interactions I had outside of formal EtE-related events. For example, in April 2015 I attended the formal launch of the Blueprint to End the Epidemic outside The Gay and Lesbian Center in New York City. The event received a lot of formal press, since it featured speeches from Governor Andrew Cuomo as well as a number of City officials and noted AIDS activists. However, once the launch finished I quickly tracked down Carrie, a transgender sex worker I had met about a month earlier, in hopes of scheduling an interview with her. I accompanied Carrie and a couple of her friends/colleagues to a small park off 13th Street, where the group got into an altercation with a homeless man sitting on a nearby bench that resulted in all of us abruptly dispersing. Although these two events occurred within a block of each other, in some ways they might as well have been different worlds for the power dynamics involved.
Both through my work with NY Connects and through these AI staff members, I was able to join several listservs run by the New York State Department of Health. These listservs generally include all HIV/AIDS service providers throughout the state and are meant to disseminate information regarding major state initiatives, legislation, trainings, and other related events. I learned about Ending the Epidemic events both through these listservs and through word of mouth from AI colleagues or other colleagues I had met at EtE meetings.

In addition to attending Ending the Epidemic meetings and events, I conducted interviews with 35 people either directly involved in or affected by the EtE campaign, including: Task Force members; AIDS Institute staff; health educators; service providers (e.g. doctors, social workers); researchers; and advocates. Generally, I met and made contact with potential interviewees at EtE-related events. I would approach a potential interviewee after an event or during a break, introduce myself and my project, and request an interview. I would then follow up via email and usually I was able to schedule an in-person interview within a matter of weeks. In some cases, I identified potential interviewees due to their position in the campaign (e.g. Ending the Epidemic sub-committee co-chairs) and I would simply contact these interviewees over email to request an interview, since they already knew me peripherally from meetings.

Beyond in-depth interviews and participant observation, this dissertation also draws on popular press and activist listservs. The Ending the Epidemic campaign received quite a bit of press following both Governor Cuomo’s initial announcement and the official launch of the campaign, and so I have followed and archived stories from publications like The New York Times, National Public Radio, and Capitol New York (a local Albany newspaper). In addition, efforts to “end” or cure AIDS have recently become more prominent in the news and shown more promising results. So, I have followed these generally relevant news stories as well, and the
conclusion of this dissertation considers what the Ending the Epidemic campaign means in the context of current efforts to cure AIDS as well as the current restrictive political climate under Donald Trump. In addition, I joined a number of email listservs for prominent AIDS advocacy organizations in New York, such as the AIDS Vaccine Advocacy Coalition (AVAC) and the Treatment Action Group (TAG). Perhaps the most valuable emails, though, were those I received through the ACT UP New York listserv. This very active listserv features debates among ACT UP members (often strewn with colorful language), circulates HIV/AIDS-related news items, and often is used to distribute information on protests and other events. Thus, the ACT UP listserv became extremely valuable for alerting me to current debates in the field as well as events I may otherwise have missed.

The fieldnotes and interview transcripts I have collected over the past 14 months will allow me to show how the ETE campaign has been constructed from its beginnings as an idea spawned by seasoned AIDS activists and taken up by an AIDS Institute in crisis, through the development of the Blueprint to end the epidemic in New York, and up to the early days of official implementation. The dissertation will show how different actors have worked together along the way, sometimes blurring the lines between state and society, bureaucrat and activist. At the same time, closer examinations of how data is gathered, documented and mobilized, and how PrEP is targeted and distributed, will illuminate different aspects of power distribution through the campaign and analyze what these distributions say about AIDS activism today.

Funding

While conducting my field research, I was living in New York City and paying my bills with a combination of an Enhanced Chancellor’s Fellowship from the Graduate Center of the City University of New York and my part-time pay from the NY Connects evaluation. Since the
School of Public Health at the City University of New York ran the NY Connects evaluation, technically this funding also came from CUNY. However, there were a couple of occasions when I traveled up to Albany to attend Ending the Epidemic Task Force meetings and the AIDS Institute paid for my travel out of funds they had set aside for the campaign.

Location

Due to limited funding and my own base in New York City, much of the fieldwork for this project was conducted in and around the City. When possible, I tried to attend meetings in easily accessible areas like Westchester County and I also capitalized on a couple of trips I made upstate for NY Connects work to observe at meetings and make connections for follow-up interviews. Task Force meetings also were good opportunities to learn about work being done in other parts of the state and my work with NY Connects, which focused on New York City, the Hudson region, and Western New York (Buffalo and Rochester), also kept me apprised of activities in these areas. Ultimately, I was able to conduct interviews over the phone with Task Force members living in other parts of New York State to get their perspectives on the HIV epidemic and EtE work outside of New York City. However, given that the vast majority of people living with HIV/AIDS are located in New York City and it has been a major center of AIDS activism for the past several decades, a strong focus on this area seems appropriate.

A Note on Positionality

My own identity as an educated, white, upper-middleclass, heterosexual, cis-gendered woman was never far from my mind during the course of this research. This was for many reasons. While my experience studying race, class and gender, and their intersectionality at the CUNY Graduate Center was not the least of these, my own personal experience living in Harlem for three years while also teaching at Lehman College in the Bronx probably informed my
awareness just as much. My studies at the CUNY Graduate Center gave me an intellectual perspective on race, class, and gender in the U.S. and particularly in New York City. Meanwhile, my time living in Harlem, where I was a racial minority in my apartment building and arguably of a higher socioeconomic class than most of my neighbors, but where I also encountered sexual harassment almost daily on the street, gave me a level of experiential knowledge that I would not have had otherwise.

Due to my identity, I had relatively easy access to certain “sites” and interviewees, while my identity proved a barrier in other areas. In formal venues organized by the AIDS Institute, my identity as someone who worked closely with the AI gave me a certain level of acceptance and access that I doubt I would have had without these credentials. My identity as a researcher also was helpful in many situations, since I believe people tended to view me as an “objective” outsider who was nevertheless rooting for the cause. Ironically, this dissertation aims to dismantle the view of science as an objective truth, but I recognize that this idea of objectivity probably made more people willing to talk with me while my academic credentials also made them more likely to take my opinions seriously.

Meanwhile, due to the compliments she gave me regarding my clothing and general appearance, I can’t help but think that Carrie was intrigued by my identity as an educated, upper middleclass white woman. This fascination brings to mind the testimonies put forward in *Paris Is Burning* (Livingston 1990), a documentary about New York City’s drag queen balls in the 1990s in which several of the main “characters” (who are transgender women of color living in poor areas of New York City) claim that their dream is to be a middleclass white woman. To be sure, middleclass white women like myself can traverse a number of spaces with relative ease because we are seen as unassuming and non-threatening (Frankenberg 1993). I don’t doubt that,
while my academic credentials got me through the door in a number of situations, my identity as a relatively young white woman also helped to ease this access by conveying the message that I didn’t pose any danger. However, there were certainly times when my whiteness proved to be a barrier as well. When interviewing Cassie, a transgender health activist and a woman of color, she suggested that I would have difficulty interviewing other women like her because they were unlikely to trust a white woman. In this way, my whiteness eased my passage into some spaces while hindering it in others.

**Data Analysis**

Even before I finished conducting research, I began transcribing the audio interview files by myself. I found that this process helped me to analyze my data as I went along, although I did also formally code both interview transcripts and fieldnotes. Initially, I used qualitative data analysis software (Atlas.ti) to code my data, but ultimately I found that manually coding transcripts and fieldnotes in Microsoft Word worked best for me. Although I did approach the project with major analytical concepts in mind, I largely took a grounded theory (Strauss and Corbin 1994; Corbin and Strauss 1990) approach to coding. So, I developed my coding scheme based on major themes that I found emerging from the material itself as I toggled back and forth between coding and deeper analysis, rather than building my coding scheme from the anthropological literature at the start. As I began to prepare to write the dissertation and also applied for dissertation writing fellowships, I started to bring my data together with the literature to develop a detailed outline of the dissertation. This detailed outline was my first concrete step toward analyzing the material as a whole and it has served as the backbone of the dissertation since I began to write. While I did not specifically aim to take the extended case method approach to analysis (Burawoy 1998; Gluckman 1940), I did find myself paying particular
attention to moments of conflict while analyzing my data. These seemed to be the more productive moments in the campaign; moments during which Ending the Epidemic took on a more definitive shape or direction.

**Participant Profiles**

In addition to relying heavily on participant-observation in this project, I also conducted formal interviews with 37 people either directly associated with or affected by the Ending the Epidemic campaign. I sought out potential interviewees based on either their position within the campaign (e.g. campaign planners and organizers, Ending the Epidemic Task Force members) or their potential to be affected by it (e.g. young people, transgender women). When seeking out “community members” who might be affected by the campaign, I generally approached people who already worked in the HIV/AIDS field in some capacity and who were either known to represent a group of particular interest to EtE organizers (e.g. transgender women of color), or who spoke up in an EtE-related meeting or event to express a strong opinion about the effects of the campaign on the community they felt they represented. The table below illustrates the breakdown of interviewees by primary professional activity, including Ending the Epidemic Task Force members:

**Table 1: Interviewees’ Professional Backgrounds**

<table>
<thead>
<tr>
<th>Task Force</th>
<th>Government Worker</th>
<th>Service Provider</th>
<th>Researcher</th>
<th>Activist</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>16</td>
<td>7</td>
<td>20</td>
<td>6</td>
</tr>
</tbody>
</table>

Out of the 35 people I interviewed, 16 were Task Force members. I chose to focus heavily on Task Force members because the Ending the Epidemic Task Force was integral to establishing the priorities and principles of the campaign by developing the Blueprint document that would serve as a guideline for Ending the Epidemic moving forward. Further, because the Task Force
members were drawn from among the most prominent people in the HIV/AIDS field across New York State, these interviewees also fell within other categories of people I identified as integral to understanding the workings of the campaign; government workers, service providers, researchers, and activists. I give a more detailed description of each of these categories of interviewees below. However, I put these categories forward as a guide more than as strict definitions. Not only are Task Force members also service providers, government workers, researchers, and activists or advocates in their daily lives, but in many cases those who work in the HIV/AIDS field in general will identify as an advocate or activist to some extent. While I offer some definitions of my own below to frame the ways in which I considered interviewees to fall into one category or another, I nevertheless try to reflect some of the fluidity of identity in the HIV/AIDS world here.

In addition to describing interviewees by profession, I also offer a small breakdown of demographics:

**Table 2: Interviewee Demographics**

<table>
<thead>
<tr>
<th>Youth</th>
<th>Gay/MSM</th>
<th>Person of Color</th>
<th>Person Living w/HIV/AIDS</th>
<th>Woman</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>5</td>
<td>17</td>
<td>4</td>
<td>16</td>
</tr>
</tbody>
</table>

Since HIV/AIDS tends to disproportionately affect people of color in the U.S. and this dissertation focuses on inequality around gender and race, I made a conscious effort to over sample women and people of color. Hence, 46% of interviewees were of color and 43% were women, with some overlap between these two groups. In fact, 11 of the women interviewed were women of color; that is 73% of the women interviewed and 31% of all interviewees.

Although I did not ask interviewees directly about sensitive aspects of their identity, such as gender or sexual identity or HIV status, I did make an effort to seek out certain interviewees
who were publicly known to represent particular populations that are likely to be affected by Ending the Epidemic. One of the women counted in the table above is transgender and a known activist in the transgender community in New York City. I also attempted to interview a prominent trans male activist, but scheduling issues prevented us from connecting in person. I was, however, able to gather some input from him via email. Further, I suspect that the numbers I have cited here regarding interviewees who identify as gay or a man who has sex with other men (MSM), or as a person living with HIV or AIDS (PLHA) are a little bit low. However, I was not able to confirm these identifications one way or the other without asking interviewees for sensitive information.

Task Force Members

Following some initial hiccups when invitations were extended to join the Ending the Epidemic Task Force in October 2014 (several members representing minority groups were left off the list), the Task Force ultimately was comprised of 63 members representing a range of organizations, government bodies, research universities, and interest groups throughout New York State (e.g. the Latino Commission on AIDS, the Erie County Department of Health, the City University of New York, the American Indian Community House). In most cases, those on the Task Force were prominent members of their home institutions; directors of organizations and major AIDS service programs, widely-published researchers, or prominent activists. Given that the governor’s office technically issued the directive to convene the Task Force, it follows that those involved would be the most prominent and established representatives of the field. Indeed, particularly when it comes to issues of state, power often demands power.

Perhaps it is no surprise, then, that 43 of the 63 Task Force members (68%) were men (including one transgender man), 39 (62%) were white (both women and men), and 38 (60%)
had some level of higher education beyond an undergraduate bachelor’s degree. Over one quarter (17 members or 27%) of the Task Force Members were white men with an advanced degree. However, once the initial list had been revised to include a few prominent advocates initially left out (more on this in Chapter 1), the Task Force representation was over one-third people of color and included prominent advocates representing transgender people (both men and women), MSM of color, and women of color.

Ultimately, I interviewed the main Task Force organizers (some detailed below under “Government Workers”), the co-chairs of each of the four sub-committees and the sub-committee on priority populations that was established at the November 18th, 2014 meeting. I also conducted interviews with some Task Force members that focused on their other work related to Ending the Epidemic and not specifically on the Task Force. Further, much of my knowledge of the Task Force in general came from observing four of the five official meetings, which would typically last an entire day, and where I was able to both listen to formal discussion and engage in informal side conversations.

Government Workers

Since Ending the Epidemic (officially) was a directive handed down from Governor Cuomo’s office, the New York State Department of Health’s AIDS Institute (AI) has taken responsibility for overseeing the initiative, and government usually bears the brunt of public health work, government workers are key players in the campaign. In total, I interviewed five people who worked for state, city, or county government. This included three staff members from the AI; the Director and the campaign’s two main organizers based in the AI’s Office of Planning and Community Affairs. From the New York City Department of Health and Mental Hygiene (DOHMH), I interviewed the Assistant Commissioner of the Bureau of HIV/AIDS
Prevention and Control. I also interviewed a supervisor in the STD/HIV Control Program at an upstate County Department of Health.

The AIDS Institute (AI) was established under current Governor Andrew Cuomo’s father, Mario Cuomo. It was the first governmental institution of its kind in the U.S. and several decades into the epidemic it continues to be innovative and influential. Throughout the course of my fieldwork, AI staff would mention having spoken with other cities that were launching initiatives similar to Ending the Epidemic to help them get started, and the AI’s Medical Director regularly flew to other continents to consult on international projects. In short, the AI seems to have a far reach for a state government institution. During the course of my fieldwork I was able to interview the AI’s Director, Dan O’Connell, who served as one of the co-chairs of the Ending the Epidemic Task Force and who ultimately turned the Task Force’s recommendations and conversations into the final Blueprint to end the epidemic. Dan assumed the role of Director in 2013 after the previous Director of over 20 years stepped down, and at least one other interviewee told me he didn’t think the campaign would have been possible without Dan in his current role. In addition, I interviewed Johanne Morne, the Director of the Office of Planning and Community Affairs. As of June 2016, Johanne had been appointed Dan O’Connell’s replacement as Director of the AIDS Institute in preparation for Dan’s planned retirement. This announcement came as no surprise to me and seems to have been well received by AIDS activists since Fred, a prominent member of ACT UP, sent an email to the listserv breaking the news and expressing his happiness with the appointment that was echoed by others. During the initial phases of Ending the Epidemic, Johanne was the main organizer, orchestrating logistics for community listening sessions, Task Force meetings, and other public-facing events, and in this way she often served as the AI’s face of the campaign on the ground. I also interviewed
Johanne’s close colleague, Laura, who also works in the Office of Planning and Community Affairs and acted as Johanne’s deputy in many respects, sharing in the daily responsibilities around coordinating the Task Force and related events.

At the New York City DOHMH, I interviewed Dr. Demetre Daskalakis. Dr. Daskalakis assumed the role of Assistant Commissioner of the Bureau of HIV/AIDS Prevention and Control shortly before the Ending the Epidemic campaign started up. A long time practicing physician who specializes in HIV/AIDS, Dr. Daskalakis has continued to see patients even after assuming his new role. Dr. Daskalakis also is known for his many years of activism and has been called a “gay health warrior” (Krisch 2014) for initiatives like visiting gay nightclubs to conduct HIV and STI tests and provide vaccinations. During the course of my fieldwork, I heard some people speculate that Dr. Daskalakis had been brought into his current position as a direct result of his activist work, since the Commissioner of Health for New York City, Dr. Mary Bassett, often is seen as taking a social justice-oriented activist stance herself. In addition to his role as a DOHMH employee, Dr. Daskalakis also was a member of the Ending the Epidemic Task Force, where he served on the Prevention sub-committee.

Finally, in an attempt to better understand the government’s role in public health closer to the ground, I interviewed Whitney, who is a supervisor in the STD/HIV Control Program at a county Department of Health in upstate New York. I got to know Whitney through her involvement with NY Connects, where she showed tremendous enthusiasm for working with a state-driven initiative. So, I used our interview as an opportunity to ask about connections she sees between NY Connects and Ending the Epidemic, and how she saw her own role at the county level fitting in to the overall EtE initiative.
In addition to these five interviewees, I had numerous opportunities to observe and talk informally with staff from the State Department of Health and the NYC DOHMH. Not only were many government workers present at EtE Task Force and AIDS Advisory Council meetings, but some also attended other meetings and events not directly related to Ending the Epidemic that I attended as well, such as the monthly NYers4PrEP Task Force meetings. Informal chats over lunch at Task Force meetings or while waiting for a NYers4PrEP meeting to begin proved to be crucial for learning about day-to-day activities in these institutions that supported the campaign.

Service Providers

I define this group very broadly to include anyone who works in a clinical or supportive service setting. This includes doctors, pharmacists, health service coordinators, health educators, and religious leaders. In total, I interviewed five medical doctors. Several of these doctors were on the Ending the Epidemic Task Force, but others I sought out for their particular expertise, such as one doctor who works specifically with young people (most of whom are of LGBTQ experience and are young people of color) and another who works primarily with Caribbean populations in Brooklyn. I also interviewed one pharmacist and five clinical service providers, including an Associate Vice President of Research and Quality at a large upstate health provider and a PrEP Coordinator at a major hospital in New York City. In addition, I interviewed a youth health educator, who is herself a young woman, in Queens, and a pastor who runs a “radically inclusive” ministry in both New York City and New Jersey.

Similar to my experience among government workers, I also had many opportunities to observe and speak informally with a number of service providers in settings such as the regional listening sessions that the AIDS Institute organized throughout the state to spread the word about Ending the Epidemic, NYers4PrEP Task Force meetings, and informational events not directly
affiliated with EtE (e.g. educational PrEP panels). In these settings, I was able to listen to providers talk amongst themselves about the implications of EtE and express their opinions about the campaign’s priorities.

Researchers

Many of the researchers involved in the early stages of Ending the Epidemic were drawn from major universities in New York City all of which have major centers and/or prominent faculty that work on HIV/AIDS. For this project, I interviewed four formal researchers; three are based at Columbia University in New York City and one at the City University of New York. Three of the four are full professors at their respective institutions. One of the researchers, based at a school of public health, is a research coordinator. Two of the researchers served as sub-committee co-chairs on the Ending the Epidemic Task Force.

In addition to the formally recognized researchers listed above, I would also add that some of the activists I interviewed should be considered researchers as well. As Epstein (1996; 1995) acknowledges, many early AIDS activists built their reputations learning the science of HIV/AIDS and then advocating for changes in research protocols to make anti-retroviral drugs available more quickly. While these activists may not always be directly involved in conducting research, surely their work has been heavily focused in this domain and much of their knowledge may rival that of researchers trained formally in the academy. David, for example, was an original member of ACT UP who now runs an organization that writes research papers and policy briefs about HIV/AIDS.

Activists & Advocates

Here I differentiate between activists and advocates. AIDS activism has a history in the U.S. that often is associated with taking to the streets, and part of the argument I make in this
dissertation is that it is important to re-think who counts as an “activist” and under what circumstances in order to create a more equitable activist space. However, given the history of AIDS activism in New York, as well as the degree to which EtE organizers clearly made an effort to include an activist perspective in the campaign’s planning stages, I felt it was important to seek out interviews with AIDS “activists,” which I define as people who speak out and take action openly and publicly on behalf of their respective communities. This includes historical AIDS activists, such as members of ACT UP, several of whom played prominent roles on the Ending the Epidemic Task Force. In fact, Charles King served as “community” co-chair of the entire Task Force and Mark Harrington co-chaired a sub-committee. I was able to interview both Charles and Mark in addition to two other members of ACT UP (including one woman) who were also on the Task Force. In addition, I include three other interviewees in my definition of “activist;” one woman living with HIV who has been featured in a prominent public health campaign, the pastor of a “radically inclusive” church, and a PrEP educator who has started an online group comprised of thousands of members to share information about PrEP. Through their respective work, I believe each of these people meets the definition of “activist” just as much as members of an organization like ACT UP, even without literally taking to the streets.

In addition to activists, I include a much broader category of interviewees I call “advocates.” For the purposes of this dissertation, an advocate is someone who works on behalf of a cause or promotes it in their daily life without being publicly vocal. I suspect that most of the people I interviewed would fit into this category, since working in the HIV/AIDS field generally involves some level of advocacy out of necessity. This may be in the form of policy work, assisting an HIV-positive patient with securing affordable housing, or conducting research that promotes the health and well-being of people living with HIV/AIDS.
Outline of Chapters

CHAPTER 1: Is the End of AIDS the End of Inequality? This chapter explores how Ending the Epidemic participants understand and work toward the “end” of AIDS in the context of the origin and early implementation of the campaign. Building on the literature around AIDS activism outlined above, the chapter considers the formation of Ending the Epidemic in the context of campaign participants’ understanding of the “end” of AIDS as a moment to “make history” by ending inequalities. To what extent is this mission institutionalized in the campaign itself and where does it miss the mark? As such, the chapter traces the origins of the Ending the Epidemic campaign from a plan hatched by two prominent AIDS activists through the creation and work of the Ending the Epidemic Task Force, the development of a Blueprint to end the epidemic in New York State, and the official launch of the campaign by Governor Andrew Cuomo in April 2015. Taking into consideration the dynamics of each of these formative moments, I examine how AIDS activism works in this particular context. While Farmer (2006) and many others have shown that inequality both drives and sustains the spread of HIV, how do different actors involved in EtE work together across lines of inequality towards a grand shared vision? What continues to divide them, how do they handle these divisions, and what becomes of this work?

CHAPTER 2: The Implementation Phase: What Is “Community” and What Does It Do? This chapter examines the ways in which the concept of “community,” long an important aspect of AIDS activism, is understood and used in the implementation phase of the EtE campaign. While Governor Cuomo launched the Blueprint in April 2015, the AIDS Institute didn’t hold its official regional implementation meetings across the state until August. In the interim, previously established mechanisms for organizing AIDS service providers were brought under the EtE
“umbrella.” These mechanisms include NY Connects, a state-run program to improve linkage to and retention in care for people newly diagnosed with HIV, and Informed NY, a program similar to NY Connects that runs only in New York City and focuses on HIV testing. The chapter analyzes the dynamics of state- and city-run efforts to end the epidemic, as well as official implementation meetings held both by the AIDS Institute and by activist groups in New York City. These actions raise the question of how government and civil society ultimately work together to implement a large-scale initiative like EtE, and how “community” is mobilized in the interests of the campaign. In some respects, government efforts appear to be an example of the neoliberal push to de-centralize healthcare management and place more responsibility on individual providers (Larsen and Stone 2015), and some of this responsibility falls on individual community members as well, raising questions around when and how to best engage “community” in a contemporary health campaign.

CHAPTER 3: The Power of Data This chapter focuses on the politics of knowledge in Ending the Epidemic, analyzing how data, documentation, and knowledge management reflect power relations within the HIV/AIDS field in New York. Epstein (1995) has shown how, in the early days of the AIDS epidemic, the generation of credible scientific knowledge was relatively democratic, and allowed for contributions from AIDS activists and the public in a way that is unusual for scientific research. Still, as detailed above, gendered and racialized inequalities persisted, and women and people of color struggled for representation (Susser 2009). Knowledge generation and management, particularly who has the authority to participate in generating and disseminating scientific knowledge, has therefore been a major touchstone in the field for much of its history. In the case of EtE, data collection and tracking is a major component of the campaign. And while New York State in particular is making concerted efforts to democratize
data and make it more publicly transparent, the type of data the state generates in the first place is determined by high-level decision-makers who make decisions about what kinds of information count as meaningful. In this respect, the question remains as to how much making data “transparent” really makes knowledge generation and management more open and democratic. What remains opaque in a campaign that prioritizes transparency?

CHAPTER 4: Mobilizing PrEP This chapter analyzes the mobilization of pharmaceuticals across sectors in the Ending the Epidemic campaign. As one of the three main pillars of EtE and a relatively new technology (the HIV drug Truvada was only approved as pre-exposure prophylaxis in 2012), the roll out of pre-exposure prophylaxis (PrEP) on a large scale virtually requires all sectors involved in the HIV response to work together. Indeed, prior to announcing the campaign the state had to negotiate prices with Truvada’s manufacturers under the assumption that the Department of Health would have to provide PrEP for free or at very low cost to many who qualify. In addition, a number of activists and service providers in New York City have been meeting as the PrEP for NYC Task Force for the past several years to coordinate messaging, service delivery, and learning across the city. However, rolling out PrEP on a large scale across the state presents some major challenges. Namely, while PLHA have been able to organize as a single community in the past, HIV-negative people do not share this identity. Further, for many of those who have the potential to benefit the most from PrEP the large-scale distribution of pharmaceuticals raises the specter of historical patterns of racist drug testing and treatment (Abadie 2010). In this context, how is PrEP mobilized, and how are the people themselves mobilized to access a new method of HIV prevention? What are the implications and advantages of one form of mobilization over another?
CHAPTER 5: Who Should Be PrEPared? This chapter examines the gendered, sexualized, and racialized aspects of EtE’s heavy PrEP promotion. The gendered implications of PrEP have been clear from the beginning, since early studies proving oral PrEP’s efficacy focused primarily on men who have sex with men (MSM). With new HIV infections concentrated largely among MSM, particularly MSM of color, in New York State (New York State Department of Health AIDS Institute 2012), EtE has placed a particular emphasis on targeting PrEP to this population. The paradox here is that much of the EtE rhetoric aims to affirm the racialized and gendered sexualities of MSM of color while at the same time singling them out as a public health threat. In some respects, the “threat” of black male sexuality is nothing new, as it harkens back to myths of the black/brown rapist prevalent across the globe under colonialism and under U.S. slavery (e.g. Spivak 1988). In this context, parallels that are regularly drawn between oral contraceptives and PrEP during ETE meetings bring to mind attempts to medicalize, and therefore control, female sexuality and sexual risk using pharmaceuticals (Watkins 2001), as well as contentions that reproductive “choice” is only reserved for women of privilege (Davis 2009). If mobilizing PrEP is both about who is “at risk” of contracting HIV, and who is “risky” and might pass the virus on, what is the interplay between risk, gender, race, and sexuality in this case? In a marketplace that supposedly offers PrEP access to everyone who needs it, who actually has choice and who does not?

CONCLUSION: In the Conclusion, I draw together findings from the previous chapters and point to the consequences of ongoing inequalities in the response to HIV/AIDS. If we consider that Ending the Epidemic is, at best, the “beginning of the end,” then it is important to assess the current state of inequality in AIDS activism and use it to think forward. I then pose some ideas for future research and conclude by discussing my findings in the context of the current political
situation in the U.S. At this moment in U.S. history intersectionality has become particularly relevant and important. After Donald Trump was elected President in November 2016 by campaigning on a platform that was blatantly sexist and racist, the political climate in the U.S. has become notably charged and people are taking to the streets in ways we have not seen in decades. Protests for women immediately following Election Day 2017 drew millions of people across the globe. Other protests followed in the first few months of the year to support immigrants and to advocate for science. Not only is protest, as a friend of mine pointed out, “the new brunch,” but the range of issues inciting protest at the moment suggests a growing awareness that social problems affecting disparate groups of people are at least related, if not interdependent. If one of Ending the Epidemic’s main goals seems to be to address the ongoing struggle of intersectionality in AIDS activism, what is the promise of EtE in the current political climate?
CHAPTER 1 Is the End of AIDS the End of Inequality?

On October 14, 2014, the New York State Ending the Epidemic Task Force met for the first time at a hotel outside of Albany. Standing at the front of a conference room full of over 60 AIDS activists, service providers, researchers, and government employees from across the state, Task Force co-chair Charles King called on the group to pay homage to the history of the movement with their work, and to aim for a goal even bigger than ending New York’s AIDS epidemic. Referring to an “unseen balcony” where friends and colleagues who had died with AIDS were sitting, King said, “We who survived those years owe it to these, our heroes” to do this work. He went on, “The end of AIDS is what brought us all to this table, but what we are about is much bigger than AIDS...if we do our job well, we will have not only ended AIDS, but we will have helped to make New York a better place. A place where those cast to the margins find themselves at the center of our care and concern.” Further emphasizing this point, King recalled a 1988 rally outside of the U.S. Department of Health and Human Services, where LGBT activist Vito Russo made a speech:

“Someday, the AIDS crisis will be over,” he said, “Remember that. And when that day comes...there will be people alive on this earth. Gay people and straight people...who will hear the story”...that there was a terrible disease “and that a brave group of people stood up and fought and in some cases gave their lives so that other people might live and be free. And then, after we kick the shit out of this disease, we’re gonna be alive to kick the shit out of this system, so that this never happens again.”

It is the fulfillment of this vision, King said, that brings the Task Force together.

As discussed in the Introduction, in addition to being emotionally meaningful to activists who have lost friends and lovers to the virus, the U.S. AIDS epidemic is meaningful on a social level for the way it encompasses and dramatizes inequalities at the nexus of sex and sexuality, gender, class, and race. It is unsurprising, then, that while campaign participants regularly refer
to the state’s numerical definition of the end of the epidemic in meetings and at public events, they often also make reference to a grander sense of vision around fixing inequalities and making history. In one Ending the Epidemic Task Force meeting, a participant said, “What we’re trying to do is fix disparity,” while at a town hall meeting in Harlem one representative from the New York City Department of Health and Mental Hygiene (DOHMH) suggested that if Ending the Epidemic is successful, it will usher in a “new epidemic of love, respect, and justice.” In both cases, the speakers suggest that EtE will ultimately have social effects far beyond ending the AIDS epidemic. The underlying message is that the end of AIDS is the end of injustice and inequality.

For Task Force members, this grand vision seemed to be a galvanizing point and a shared mission. When describing the Task Force process, members commonly referred to “walking across a bridge before building it,” “building this plane while we fly it,” and “This is a train that is moving fast and we are building this train as we are going.” The implication seemed to be that the process was unprecedented, almost precarious because it had never been done before. Yet, everyone was in it together. However, some also expressed ambivalence around the idea of ending AIDS, predicting that “In 25 years, we’ll be coming back [to lobby at the state capital] for the end of us.” As Rapp (2000) has noted in her discussion of prenatal genetic testing, ambivalence is a common response to a situation in which the potential to eradicate a deadly disease raises moral questions about the value of those currently living with the disease. In this sense, ending AIDS is not an unequivocal moral good if it undermines the value of PLHA, many of whom represent groups (e.g. sexual minorities, people of color) already undervalued by society at large. Addressing inequalities is particularly important in this context and Task Force participants seemed to be aware of this as well. For example, Charles King would often note that
even if the campaign reached its numeric goal of only 750 new infections per year in New York, but all of these infections were concentrated among one particular group (he often cited MSM of color), this would be a failure.

A number of anthropologists (e.g. Baer, Singer and Susser 2013; Susser 2009; Farmer 2006; Singer 1994) have shown that inequality both drives and sustains the spread of HIV, and New York State has a relatively strong track record in providing supportive services to address these inequalities, particularly for people living with HIV or AIDS. However, the AIDS activist movement itself has long grappled with internal divisions and inequalities along the lines of gender, race, and class. Given this history, this chapter analyzes the early trajectory of the Ending the Epidemic campaign (Chapter 2 probes the beginnings of the campaign’s “implementation” phase from April – December 2015), looking specifically at the development of the campaign from its conception in July 2012 through the final meeting of the state-appointed Ending the Epidemic Task Force in January 2015, and the official launch of the Blueprint to End the AIDS Epidemic in April 2015. In this way, I attempt to fit the grand vision of ending disparities with the internal dynamics of the campaign itself, paying particular attention to the ways in which the community of AIDS activists is configured, how they work with state government, and to what ends. What are the power dynamics of contemporary AIDS activism as demonstrated by the politics of EtE? How do these power dynamics make their way into policy-making processes? To what extent is the grand vision of Ending the Epidemic both enacted and institutionalized in and around the Task Force process?

**Background: What Motivated the Campaign**

While the policy environment has clearly coalesced over the past several years to create the right conditions for an initiative like Ending the Epidemic, campaign founders cite a couple
of specific factors that motivated them to act. On the one hand, while the Obama administration was responsible for launching the country’s first comprehensive HIV/AIDS strategy, the plan was widely criticized. As Mark Harrington, one of the activists involved in starting the ETE campaign, noted, “At the same time as Hillary Clinton came out with the AIDS-free generation and the plan to eradicate pediatric AIDS around the world,” the Obama administration was promoting a “shitty” domestic strategy. In response, “…we [Mark Harrington and Charles King] started talking about whether or not…there was an opportunity to work together, since we both were critical of the National AIDS Strategy” and thought they could use New York as a test platform to try a more “ambitious” strategy.

Further, despite the state’s many successes fighting the epidemic thus far, and the supportive environment state and city agencies have managed to create, several years ago the New York State Department of Health’s AIDS Institute faced a crisis. The AIDS Institute was formed in 1983 by then-Governor Mario Cuomo (current Governor Andrew Cuomo’s father) to respond to the rapid proliferation of AIDS in the state. According to a report issued by the AIDS Institute on its 25th anniversary, its charge was:

(a) to develop and promote scientific investigations into the cause, prevention, methods of treatment, and cure of the acquired diseases of immunosuppression;

(b) to develop and promote programs of professional education and training and improvements in instrumentation as necessary adjuncts to such scientific investigations;

(c) to develop and maintain a clearing house within the department for information collected on acquired immune deficiency syndrome, including a catalogue of the existing medical literature and the results of existing epidemiological studies;

(d) to develop and promote an outreach campaign directed toward targeted high risk populations to provide coordinated information regarding the treatment and counseling programs and sources of financial assistance available; and
(e) to promote the availability of supportive services for affected persons (New York State Department of Health, AIDS Institute 2010:5).

In short, the AIDS Institute was created to coordinate AIDS-related research and policies across the state, including supportive services. The creation of the AIDS Institute and its ability to distribute grant money made New York the first U.S. state to fund AIDS research (Ibid.).

After almost three decades in existence, a number of interviewees reported to me that the Cuomo administration was planning to effectively dismantle the AIDS Institute and distribute its functions across various government agencies. AIDS activists started to rally around defending the AIDS Institute and, as one activist who became involved in Ending the Epidemic early on noted, “It all kinda seemed to come together like, ‘Oh yeah, we could have a plan to end AIDS, and here the AIDS Institute is being threatened…’” As this same activist and several others reported, a new campaign to end AIDS in New York State was seen as a way to save, and even reinvigorate, the AIDS Institute. So, when the former director of the AIDS Institute, who had been running the institution since 1989, retired in 2013, the time was especially right. As one of the founding campaign activists said, “I don’t think this would have happened if [the former director] had been there [the AIDS Institute],” since the director thought a campaign to end AIDS in New York would serve as another reason to take resources away from the AIDS Institute, rather than a reason to increase funding. However, the director was still deeply concerned about the potential budget cuts and, according to the same activist, he timed his retirement so that he could resign in protest if necessary. In contrast, the new director of the AIDS Institute, Dan O’Connell, was very much in support of the idea and threw the weight of the AIDS Institute behind it. The time was right for New York State to make a real attempt to end its AIDS epidemic.
Garnering Support for Ending the Epidemic: Building on the Early Days of AIDS Activism

While the stars had seemingly aligned to create a hospitable policy environment for Ending the Epidemic, organizing and launching the campaign involved extensive coordination both among AIDS activists, and between this community and state government. In late 2012 (following the summer 2012 arrests in Washington D.C.), a group of researchers, clinicians, community-based organizations, and HIV/AIDS service “consumers” came together to begin discussing the idea of ending the epidemic. According to Charles King, the next meeting didn’t take place until May 2013 at Columbia University, at which point Housing Works (run by Charles King), Treatment Action Group (run by Mark Harrington), and the AIDS Community Research Initiative of America (ACRIA) were the lead organizers, and had agreed to invite government representatives. According to Charles, Dan O’Connell attended that meeting along with the director of the Office of Planning and Community Affairs, and the state’s Medicaid director: “I walked him [the Medicaid director] out the door and was like ‘Man, you gotta do this for us.’”

This meeting had two significant results. First, following the meeting over 40 LGBT advocacy organizations signed a joint letter to the governor calling for an end to the AIDS epidemic in New York State. Charles King notes that the composition of names on this letter was important, first because this was the first time that LGBT organizations had been part of AIDS advocacy in decades, and second because these organizations “had far more muscle with the Cuomo administration.” After this first meeting with activists, Dan O’Connell says that he was able to get provisional approval to move forward with the plan, while activists started meeting with the governor’s office and with the Deputy Commissioner of Health. Another activist noted of the Deputy Commissioner, “She was immediately on board and became our champion...,” and
Dan O’Connell suggests this may have been because activists appeared to have built an unusually broad coalition amongst themselves: “I think what impressed [her] was the fact that there were a lot of groups that were at the table who normally didn’t sit at the table together.” As one of the activists who became involved early on said in an interview, “It just sort of exploded from there,” and indeed the final version of the Blueprint to End AIDS refers to the May 2013 meeting as the real starting point of the Ending the Epidemic initiative (New York State Department of Health. 2015, 9).

The second major result of the May 2013 meeting was a working paper titled “Revitalizing the Response: What would be the key elements of a New York plan to end AIDS?” This paper uses state-wide statistics and references to authoritative sources such as academic papers and the National HIV/AIDS Strategy to make the case that ending AIDS in New York State is both strategic and feasible. Further, the paper outlines five components of a proposed plan to end the epidemic:

1. Adopt 21st century surveillance strategies to know the epidemic;
2. Reduce new HIV infections through increased commitment to evidence-based combination prevention for both HIV-negative and HIV-positive persons;
3. Focus on filling the gaps in the HIV continuum of care – to maximize the number and proportion of people able to suppress HIV viral load as rapidly as possible following an HIV diagnosis;
4. Assure the availability of essential services that support health, prevention, and retention in care for all New Yorkers, whether HIV-positive or HIV-negative;
5. Commit political leaders and all New York communities to leadership and ownership of the New York Plan to End AIDS. (No Author 2013)

Since the working paper on ending AIDS in New York relied heavily on increasing access to HIV treatment and chemoprophylaxis for prevention, Charles King says he then met with the state’s Medicaid director to “do the math” around putting many more people on antiretroviral medications (ARVs) and found that the cost would be prohibitive for the state. So,
beginning in late 2013, Charles started to meet with Gilead Sciences, one of the leading manufacturers of AIDS drugs. With heavy support from other community activists, he helped to broker a discount for the state by early 2014, and several other major pharmaceutical companies quickly followed suit.

Around this same time (October – December 2013), the AIDS Institute convened six “community meetings” across the state to gather local input regarding priority issues, methodologies, metrics, communications strategies, and suggested participants for the initiative, which was then called “End of AIDS” (New York State Department of Health AIDS Institute 2013). Activists throughout the state also were continuing to organize, heavily lobbying Governor Cuomo to officially announce the campaign along with his annual budget recommendations in the spring. One of the key organizing entities in this process was a group of New York City-based activists who called themselves the Kitchen Cabinet.⁷ When the governor’s office delayed announcing the campaign multiple times in early 2014, the Kitchen Cabinet drafted an op-ed for Gay City News chastising the governor for engaging with activists around this work without making an official announcement. Approximately 30 organizations signed on to this piece, which Charles King says he then sent to the governor’s office with the message that “We’d much rather do something calling the governor a hero…” Shortly afterwards, Governor Cuomo officially announced the initiative at the New York City Pride Parade on June 29, 2014. As displayed on the AIDS Institute’s “Ending the Epidemic” website, this official version of what was then called “End of AIDS” (despite some community opposition

⁷ According to one member of the Kitchen Cabinet, the group was “sort of behind the scenes feeding all the information to the governor’s people and also being a way to translate what was happening back to the community.” Although I know that this group included membership from such prominent AIDS service organizations as Housing Works, Treatment Action Group, and Harlem United, I have not been able to track down a list of members or a more concrete timeline of their meetings.
to the title) was a distilled version of the 2013 working paper proposal, comprised of only three main components:

1. Identify persons with HIV who remain undiagnosed and link them to health care;
2. Link and retains persons diagnosed with HIV in health care;
3. Facilitate access to Pre-Exposure Prophylaxis (PrEP) for high-risk persons to keep them HIV negative.

Compared with the 2013 working paper proposal, this final version from the governor’s office does not directly address political commitment to the campaign, or the working paper’s suggestion that surveillance and database systems needed to be strengthened. Still, much of this language did ultimately make it into the Blueprint to End the AIDS epidemic (see more below), which has an entire section dedicated to data monitoring and metrics (New York State Department of Health 2015). Perhaps the most noteworthy shift between the working paper proposal and the governor’s announced plan, though, is the explicit focus on PrEP in the official plan, which contrasts with the suggestion to focus on “combination prevention” for both HIV-negative (which could include PrEP and post-exposure prophylaxis (PEP)) and HIV-positive people (treatment as prevention) in the working paper. In fact, the working paper includes a diagram of prevention options along a continuum of exposure that includes such options as behavioral and structural interventions for persons unexposed to HIV and post-exposure prophylaxis (PEP) for people recently exposed (No Author 2013, 3). In contrast to the comprehensive approach to prevention laid out in the working paper, the focus on PrEP in Governor Cuomo’s announcement is striking, and I explore it further in Chapter 4.

The dynamics behind the Ending the Epidemic campaign therefore hearken back to the early days of AIDS activism in some ways, while also drawing on the influence that particular activists and organizations have developed over the past several decades. As Charles pointed out, AIDS activists had long since fractured with LGBT organizations, but they were able to bridge
this divide in order to make a savvy political move, because they knew that the LGBT organizations carried greater weight with the current administration in Albany. Further, Charles suggested the fact that so many organizations who don’t usually “sit at the table” together were backing this initiative may have inspired greater confidence from the governor’s office and encouraged the Deputy Commissioner of Health to take the effort seriously. However, it is clear from the Spring 2013 meeting at Columbia and the subsequent development of the “End of AIDS” working paper that long-established organizations like Housing Works and Treatment Action Group (TAG) have developed strategic alliances with researchers, other service providers, and government officials over the years, which has given them true convening power and allowed them to drive the initiative forward. As Epstein (1996) points out, activists behind organizations like Housing Works and TAG are original ACT UP members who have been able to draw on their gender, class, and race privilege to garner power in the field. Such activists had a clear role to play in getting EtE off the ground by using their convening power among activists in the field, as well as the political clout they have developed over the past several decades.

**Task Force Politics: Institutionalizing Power Dynamics**

*Forming the Task Force*

Over the summer of 2014, the Kitchen Cabinet was asked to submit recommendations to Governor Cuomo’s office for members of a task force (the Task Force) to develop the state’s blueprint (the Blueprint) to end AIDS. During this time, Charles King was invited to be the Task Force “community co-chair,” but many others were not officially invited until the day before the Task Force’s first meeting on October 14, 2014 in Troy, NY (outside of Albany). The Task Force was officially co-chaired by Charles King and Commissioner of Health Guthrie Birkhead, though Dan O’Connell often played the role of co-chair in Dr. Birkhead’s absence. The Task
Force consisted of over 60 activists, researchers, medical service providers, and government employees from across the state who were scheduled to meet five times over the course of approximately 90 days, and meetings alternated between upstate New York and New York City.

Most of the Task Force members I spoke with claimed ignorance around how the final appointment decisions were made, but the inclusion of a representative from Gilead Sciences (a pharmaceutical company and PrEP manufacturer) proved controversial and there were several obvious omissions of people or agencies representing people of color. As one Task Force member, a woman of color, said to me in an interview:

…this is no secret, the Task Force and the drive behind really grabbing this opportunity of medications that can lower viral load and reduce HIV transmission in the name of, or kind of with the warrior cry on behalf of men of color, or MSMs of color, but there weren’t many [on the Task Force]. The whole Task Force process was very much driven by the white gay men who I grew up with who were dealing with what I call the first generation of prevention issues. And so, that was a problem, right? Women living with HIV weren’t really represented. Women of color living with HIV weren’t really represented.

Indeed, perhaps the most notable omission was Stephanie, one of the members of the Kitchen Cabinet who is a black woman from a major AIDS service organization known for working with people of color. As Stephanie said in an interview, “I don’t know what happened to this day. We got left off the list…nobody could explain to me why.” These omissions were later rectified, but in Stephanie’s case this meant calling the governor’s office directly just to be included.

Similarly Emily, a white woman and long-time AIDS activist, told me that even before the Task Force started meeting she learned of the preliminary meetings among a small group of activists. As Emily recounted to me:

I’d heard about the meetings… I asked [another activist], I’m like “There’s these meetings that are happening about ending the epidemic in New York State.” I’m like “Can I come?”…He said, “Oh, I’ll have to ask if it’s ok.” And I remember thinking “Oh

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8 Meetings were held: October 14, 2014 (Troy, NY); November 5, 2014 (NYC); November 18, 2014 (Troy, NY); December 15, 2014 (NYC); January 13, 2015 (Troy, NY).
hell no, this is not gonna be a boys’ club…It’s not gonna be this closed bullshit that happens in our community.” If you watched [the documentary] How to Survive a Plague, that happened. Let’s not repeat it…

Here, Emily points to the history of excluding women in AIDS activism and also expresses her frustration with feeling excluded early in the EtE process. Eventually, Emily was able to join the meetings, but said she felt that they were dominated by the more established white, gay male activists with little room for dialogue and collaboration. However, this dynamic changed as the meetings opened up to more activists in the field and the AIDS Institute got involved to start organizing the formal Task Force.

Who Contributes, Who Makes Decisions

Indeed, while the politics of who was ultimately at the Task Force table were controversial, the AIDS Institute in its role as organizer made clear attempts to include as many perspectives as possible. First, all Task Force meetings were open to the public (although the high security at the Department of Health’s office in New York City, not far from the World Trade Center site, was sometimes prohibitive), and the meetings also were recorded and posted to the AIDS Institute’s website. In addition, the AIDS Institute initiated and managed an open online survey where they gathered recommendations for the Task Force from interested parties across the state. Although I was not able to track these communications, it appears that announcements calling for contributions through the online survey went out over both activist listservs and directly from the Department of Health. The AIDS Institute ultimately received 294 recommendations, which totaled nearly 1,000 pages and are available on the AIDS Institute’s website (New York State Department of Health 2015, 10).

In order to efficiently handle the number of recommendations coming in, the Task Force was divided into four sub-committees: Prevention, Data, Care, and Housing and Supportive
Services. Later, a cross-cutting sub-committee on “Key Populations” formed in response to controversy around lack of representation for certain groups in early drafts of the Blueprint (detailed further below). Each sub-committee was headed by two co-chairs who oversaw the process for their particular group, coordinating conference calls between formal Task Force meetings and drafting a set of 10 recommendations, largely distilled from the online survey, to be submitted as part of the final Blueprint on behalf of their sub-committee. Here, it is worth noting the demographics of the sub-committee co-chairs. Out of eight co-chairs, while half were people of color, only one was a woman. One additional woman of color became a co-chair when the “Key Populations” sub-committee was added. None of the co-chairs were outwardly transgender. So, while the AIDS Institute made a clear attempt to include a wide range of perspectives in the Task Force process, at the end of the day it was mostly men drafting preliminary language for the Blueprint.

This is in large part because, as noted above, the gay white men who have been in the field for a long time have developed a high level of authority and political power, and have become integrated into the workings of the state. As Emily noted in our interview, “I think HIV where it was in the ‘80s [was] probably a very scary time and you didn’t have time for ego because you literally were fighting for your life and your loved one’s life. Well, now it’s an industry. It’s a business.” Certainly, the institutionalization and professionalization of AIDS activism (Seckinelgin 2016; Wohlfeiler 2002), and of social movements more generally (Staggenborg 1988; McCarthy 1973), has been recognized in the academic literature. As social movements develop and become more established with more access to resources, they often come to take on the structures, and even align with, the institutions they initially opposed. In the case of the Ending the Epidemic Task Force, statements from both AIDS Institute staff and from
prominent activists working on the campaign suggest that certain established activists have been integrated into the workings of government. In turn, activists such as Charles King called on Task Force members to work with government, rather than against it.

While activist groups such as the Kitchen Cabinet drove much of the early momentum around EtE, the AIDS Institute played a key organizing role following the May 2013 meeting at Columbia, and communication with Governor Cuomo’s office also proved crucial. From the beginning, the AIDS Institute’s Office of Planning and Community Affairs assumed administrative responsibility for the Task Force, organizing meetings, administering to the online survey, and also running community “listening forums” throughout the state both in late 2013 and during the late summer/fall of 2014. In addition, the AIDS Institute was responsible for assembling the final draft of the Blueprint, leading the director, Dan O’Connell, to joke, “This sounds like it was written by a bureaucrat…well, you’re looking at him!” As Dan later described to me in an interview, constructing the Blueprint was a process of “capturing the spirit” of the Task Force’s recommendations with a “unified voice and approach.” But, when more controversial pieces arose, Dan explained that he would consult with Charles King or with the governor’s office to get their final opinion.

From the “community” side, Charles King made it clear that working with government in the context of the Task Force meant not only sitting together at the table in practice, but also curbing old activist tendencies and approaching government in a new way. For example, Charles often speaks proudly of his arrest record from years of protest and acknowledges his role in protests waged against former New York governor Mario Cuomo in which he played the role of one of the “Mario Antoinettes.” Yet, when one ACT UP member called for a protest against the FDA during the course of the Task Force, in his role as community co-chair Charles responded,
“While I’m somebody who loves agitation...[it is] not within the purview of this task force,” suggesting that the Task Force was meant to work with government, rather than protest against it. Further, the closing speech that Charles delivered at the final Task Force meeting paid homage to Mario Cuomo (who had recently passed away), noting that while “I cut my teeth” in AIDS activism challenging the (first) Cuomo administration, Mario Cuomo should be credited with early advances in AIDS policy in New York, such as creating the AIDS Institute and the AIDS Advisory Council, and developing the country’s first formal, centralized program in response to the epidemic. After this speech, one member of the Task Force spoke up and suggested that Charles send a copy to the current governor, Mario Cuomo’s son. Later, as I traveled to the train station with several other Task Force members, one expressed his surprise that Charles had spoken of the former governor with such admiration. Another suggested that, since the Task Force meetings are recorded, perhaps Charles wanted these words “on record.”

While Charles King is particularly notable for the extensive work he does now with state government, including serving on the state’s Medicaid re-design team, a version of his story certainly rings true for many AIDS activists who have been in the field for the past several decades. When placed alongside the work that the AIDS Institute put in to coordinate the Task Force meetings and draft the final version of the Blueprint, it becomes clear that contemporary AIDS activism is increasingly in cooperation with the state, rather than against it. And indeed, state government seems very willing to share in this partnership and to put significant resources behind it. However, while some prominent activists of color have recently gained recognition through appointments to government positions and conflict on the Task Force that resulted in the creation of the “Key Populations” sub-committee, the struggle to be racially inclusive is still playing out. As evidenced by the prominence of seasoned activists like Charles King on the Task
Force, the gay white men who built credibility with research institutions and other government bodies in the early days of the epidemic continue to hold most of the prominent positions from the “community” side.

**Questioning and Changing the Status Quo**

Despite Charles King’s frequent proud assertions that every Task Force decision was “achieved through consensus,” there were frequent disagreements among Task Force members. The most notable and influential conflict took place during the November 18th meeting. At this meeting, time was allotted on the agenda for sub-committee co-chairs to read their group’s draft recommendations aloud and to elicit comments from other Task Force members. Controversy arose when Dr. Reid, one of the sub-committee co-chairs and himself a black man, read out the sub-committee’s recommendations and Damian, one of the Prevention co-chairs who is a younger black man who identifies as MSM, spoke up and said, “Nowhere on this document did it say Black MSM,” despite the fact that during the first Task Force meeting there was explicit conversation around this group. Damian went on to say that “We are consistently missing the mark,” and the Task Force should not assume that certain populations are included in broader language. Rather, he felt it was important to name these groups specifically, and “The fact that it was not recorded” was a “disservice.” These comments seemed to be directed specifically at Dr. Reid as a fellow man of color, and while Dr. Reid seemed uncomfortable, he responded that the “Point [was] very well taken.” The tension in the room during this exchange was so palpable that Charles King invited volunteers from the Task Force to set up a “key populations” sub-committee that would formulate recommendations around which populations should be particularly emphasized in the final Blueprint.
The conflict also seemed to deeply affect Task Force members. During a separate discussion with one Task Force member following the January 13th closing meeting two months later, this person independently raised his concerns about the conflict on November 18th and reflected that the tension might have arisen due to the fact that the Dr. Reid’s sub-committee was largely made up of providers, reflecting a divide between providers and advocates. During a later interview with Damian, he too spoke of the power dynamics in the Task Force, as well as the responsibility that he felt to represent his peers in such a group:

And then me being the youngest person on the Task Force and at the time being the, well, let’s be specific, being the youngest, openly HIV-positive, black, MSM on the Task Force and then walking into this room where primarily there were a lot of executives and medical directors. It became, what’s the word I’m looking for? It became real [laughs]…because here are all of these executives and medical providers that, if I’m applying for a job, I have to go to them…these are people that I look up to…What made it real was because I was now on a Task Force with them. People that I saw professionally as my superiors…we now became equals. And that became real for me. The other thing that became real for me was when I saw the room and I didn’t see others that looked like me, I realized I had a responsibility to represent and to make sure that my demographic that I am a part of, my community that I’m a part of, and that I also serve…is part of the conversation and represented in the language and the discussions that are happening.

Here, Damian speaks of feeling pressure to represent his peers because he “didn’t see others that looked like me,” but at the same time he felt that he was able to speak out on behalf of himself and his peers because he saw the Task Force as an equalizer.

It is worth noting, though, that some of the inequalities Damian experienced also served as opportunities for deeper connection and working together more meaningfully. Both Damian and his fellow Prevention co-chair, Joan, who is a seasoned activist and a woman of color, spoke independently of the relationship they forged as mentor and mentee through the process of working together on the Task Force. While Damian saw Joan as a mentor who inspired him to approach his work in a new way and to “shake things up professionally,” Joan seemed to see her
work with Damian as a continuation of the work she had done decades before with young colleagues who were dying of AIDS. In fact, Joan choked up when I asked what it was like to be part of the Task Force, saying, “being able to see [Damian] grow even in that short very concentrated process was the thing that I took from it.”

Thus, Damian’s conflict with Dr. Reid reflects multiple inequalities in the Task Force; as Damian notes, he was the only young, openly HIV-positive, gay man of color at the table, and another Task Force member suggested that the conflict further reflected a divide between (traditionally more powerful) physicians and the activists in the room. However, Damian felt that the Task Force itself acted as a sort of equalizer, granting him more power than he would have in another venue, and his underrepresented identity ultimately fostered a strong mentoring relationship with Joan. Further, Charles King clearly recognized the validity of Damian’s claims when he resolved the conflict by calling for a new sub-committee specifically to address these concerns. So, while several aspects of the Task Force process reflect ongoing power differentials in AIDS activism, it is clear that Damian’s participation in the Task Force and his role as a sub-committee co-chair not only gave Damian and the population he represents a more influential voice, but also helped him to forge a potentially fruitful working relationship with Joan, another prominent activist of color.

The Product of Working Together: A Comprehensive Blueprint to End the Epidemic

Ultimately, the goal of the Task Force was to develop a blueprint for New York State to end its AIDS epidemic. The final version of this document is a clear attempt to draw together all of the state’s existing programs and resources into one comprehensive vision, which has prompted AIDS Institute’s staff members to refer to it as their “strategic plan” for the next five years. Although the official version of the document was not released for several months, Dan
O’Connell reviewed all of the final recommendations one-by-one with the full Task Force at the January 13th closing meeting. In this version, the recommendations submitted by each sub-committee had been structured to fit within the three main components of the plan that were announced by Governor Cuomo’s office in summer 2014. Under the first point, “Identify persons with HIV who remain undiagnosed and link them to health care,” recommendations focus on improving access to HIV testing and increasing availability of new fourth generation testing technology. These recommendations include more traditional approaches to HIV testing, such as encouraging and enabling more testing in areas with highest risk. However, they also focus on systemic mechanisms, such as greater education around and enforcement of New York State’s HIV testing law (which mandates that all primary care providers, hospitals, and emergency departments in the state offer HIV tests to all patients between the ages of 13 and 64), and expanding the availability of certain Medicaid plans (Special Needs Plans, or “SNPs”) to HIV-negative individuals at high risk (New York State Department of Health 2015, 17-19).

The second point of the three-point plan, “Link and retain persons diagnosed with HIV in care to maximize virus suppression so they remain healthy and prevent further transmission” is a bit broader. This section points to the needs of particular populations, such as providing enhanced services to incarcerated people and, similar to the testing recommendations, recommends leveraging state Medicaid to bring more people into care. Several recommendations also involve using both state- and local-level data to identify persons not virally suppressed and link them to or retain them in care (Ibid., 19-22). These recommendations are notable for their similarity to the goals of a state-run program called NY Connects that brings HIV service providers together in regional groups across the state to share and use local-level data to improve linkage, retention, and viral suppression. As I will discuss further in Chapter 3, pre-existing
initiatives such as NY Connects have come to serve as both infrastructure and programmatic for ETE in its implementation phase.

The final point of the three-point plan, “Provide access to PrEP for high-risk persons to keep them HIV-negative,” is notable for its focus only on PrEP when earlier community recommendations included a more comprehensive approach to prevention. However, following a steady campaign from a Mt. Sinai representative, a woman, on the Task Force who conducts much of the state’s training on PrEP, all of the recommendations in this section include references to both PrEP and nPEP (Ibid., 22-24). Non-occupational post-exposure prophylaxis (nPEP) is a prevention tool that has been on the market much longer than PrEP, since occupational PEP was first introduced to prevent HIV infection in medical professionals who were accidentally exposed to HIV in the course of their work. “Non-occupational” PEP can be administered to anyone outside the medical field and its inclusion in the final version of the Blueprint indicates, on the one hand, the power of the Mt. Sinai representative’s voice as both a long-time activist who is clearly respected in the field, and also as someone who took every opportunity during Task Force meetings to push for the consistent inclusion of nPEP in the document. On the other hand, the many references to nPEP, as well as the inclusion of two additional sections of the report on reducing new infections to 750 and “Getting to Zero,” reflect a strong commitment from Task Force members to push forward an agenda much grander and more comprehensive than the three-point plan that was officially released by Governor Cuomo’s office in June 2014.

Beyond the recommendations included under the three-point plan, the Blueprint includes recommendations specifically aimed at reducing the number of new HIV infections and disease progression in the state, and a final section called “Getting to Zero.” The section on reducing
new infections acts as a sort of catchall for broad recommendations around: increasing access to services for particular populations, such as LGBT populations, homeless youth, people who use drugs, and people living in rural areas; instituting comprehensive sexual health education in schools; developing an HIV peer workforce and increasing employment opportunities for PLHA; and increasing access to stable housing across the state. This section is where the Task Force’s goal of creating a comprehensive plan becomes most apparent, and also where the structure of the Task Force itself becomes clear, since the recommendations were obviously drawn from multiple thematic sub-committees.

Referring to the UNAIDS goals of zero new HIV infections, zero discrimination, and zero AIDS-related deaths (Ibid., 29), the “Getting to Zero” section of the Blueprint outlines high-cost, high-level recommendations that would get New York State to a place where “the only thing left to attain is a cure for HIV to help those currently living with the virus” (Ibid.). These recommendations mainly focus on legislative reform, such as passage of the Healthy Teens Act, which requires that all school districts develop and institute an age-appropriate and medically accurate sexual health curriculum, and the Gender Expression Non-Discrimination Act (GENDA), which would standardize and unify civil rights protections for transgender people in New York State. As one of the government officials who drafted the Blueprint noted, though, “without that there were gonna be a lot of unhappy people” who thought the big things they thought needed to be done wouldn’t even be referenced. According to this official, the GTZ recommendations allow for referencing these pieces without making it look like the whole plan is a huge “budget ask,” and without asking for things that aren’t yet possible in the current policy environment. In short, at this point in time the GTZ section of the Blueprint, which actually aims to “eliminate” HIV and AIDS according to Dowdle’s (1998) definition, is largely aspirational.
Finally, following the work of the “Key Populations” sub-committee, the Blueprint specifies that “New HIV infections do not happen in isolation, but rather come tied to numerous contextual factors,” such as poor health care, poverty, mental health issues, and geographic disadvantage (New York State Department of Health 2015, 15). This framing is in line with presentations the sub-committee made during the course of the Task Force process, and also with an interview I conducted with one of the sub-committee’s co-chairs, who said that when it comes to identifying key populations, it is “Not [about] who they are, but rather what they do or is done to them in a context of inequality, poverty…” However, the Blueprint does specify that certain populations are especially affected by overlapping contextual factors, such as MSM (especially black and Latino MSM), transgender people, women of color, people who use drugs, and sero-discordant couples (Ibid., 15-16).

In summary, the Blueprint recommendations reflect both the Task Force process and its politics while advancing the “grand vision” of ending AIDS. Taken together, all of the recommendations clearly aim to provide a comprehensive approach to ending AIDS by addressing the epidemic at multiple levels, from services on the ground to state-level legislation. The breadth of themes and populations addressed, and particularly the language around poverty and inequality included in the section on key populations, also suggest a concerted effort to address the drivers of the epidemic at their intersections. Further, Task Force members who I interviewed following the official end of the process, while noting the very short timeframe, were consistently positive about what they feel they achieved: “we worked fast, but we worked comprehensively.” Indeed, the final Blueprint also seems to reflect input from Task Force members representing different demographic groups. Most notably, this includes Damian’s comments that sparked the creation of the “Key Populations” sub-committee, but also Emily’s
insistence that nPEP always be included alongside references to PrEP, as well as the GTZ section, which was specifically added so that there wouldn’t be “a lot of unhappy people” once the Task Force concluded.

Advocating for the Blueprint: The Changing Face of Mobilization

While the Task Force was time-limited and charged only with developing the Blueprint, at the final meeting on January 13, 2015 the co-chairs announced the creation of a smaller subcommittee of the AIDS Advisory Council (a standing body created by statute that is meant to advise the Commissioner of Health and the AIDS Institute) to oversee the work moving forward. This sub-committee would be co-chaired by Charles King and Marjorie Hill (a woman of color who is the current chair of the AAC), and while the AAC meetings are technically open to the public, the co-chairs of each Task Force sub-committee were asked to submit two names from their particular group to serve on the new sub-committee.

At this point, though, the biggest task ahead was to officially launch the Blueprint. Although the Task Force co-chairs announced that the Blueprint was finished at the last meeting, and Dan O’Connell promised that he would not change a word moving forward, the actual document was not released. Instead, the Task Force organizers were hoping to stage an event at which the governor would officially accept and launch the Blueprint, thereby publicly signaling his political commitment. However, despite “constant nudging” from activists, the governor’s office continually delayed the launch.

During this time, activists adopted a multi-pronged approach to pressure Governor Cuomo’s participation. While Charles King reports having had meetings and discussions with the governor’s counsel and the Deputy Secretary for Health, a group of organizations and individuals that had started meeting as the “End AIDS NY 2020” coalition during the course of
the Task Force galvanized support for the cause on the ground. One of the coalition’s biggest achievements was Legislative Education Day on March 11, 2015. While organizations typically have one day in March when they travel to Albany and lobby for AIDS, this year they decided to focus their messages on garnering support and resources for Ending the Epidemic. So, several “End AIDS NY 2020” member organizations, including Housing Works and Voices of Community Activists and Leaders (VOCAL-NY), arranged for buses to transport activists from New York City to Albany for a day of lobbying. Since I received several calls and emails ahead of the date to confirm my attendance, I knew that participation in the lobbying day activity would be high, and I later found that the organizers estimated approximately 500 people had ultimately attended.

While buses left from various locations throughout the city, I had signed up for one of the VOCAL-NY buses departing from the Bronx, which was closest to my apartment in Harlem. Upon boarding the full bus, I quickly became aware that I was one of only a few white people present, which I believe reflected the demographics of the pickup location, as well as VOCAL-NY membership in general. As we got started, one of the lead organizers on the bus distributed envelopes with $15 for lunch and a roundtrip MetroCard; a common practice in AIDS activism to ensure that all are able to participate. Once in Albany, we attended a large rally in the main atrium of the capital building, an imposing three-story “well” of granite, where various state legislators voiced their support for the Blueprint. This included Tracie Gardner, a Task Force member, in her new role as Assistant Secretary of Health, who called out “Hey, family!” to the

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9 According to one of End AIDS NY 2020’s flyers, this group included: ACRIA, Albany Damien Center, Amida Care, Brooklyn Community Pride Center, Correctional Association of New York, Jim Eigo (ACT UP), Empire Pride Agenda, GMHC, Harlem United, Harm Reduction Coalition, HIV Law Project, Housing Works, Latino Commission on AIDS, Legal Action Center, Peter Staley (activist), Rev. Moonhawk River Stone, Terri L. Wilder (Spencer Cox Center for Health), Treatment Action Group, Trillium Health, VOCAL NY.
activists assembled as she took the podium. The political leaders were then followed by a string of activists who had clearly been chosen to speak for specific constituencies, such as women, prisoners, people who use drugs, and transgender people; a clear nod to the history of identity politics in the movement, and perhaps also a response to critiques that certain communities had been underrepresented on the Task Force.

Following this rally, some activists joined a large protest outside while I joined one of the small groups that had signed up to lobby. In addition to myself, my group consisted of four men from ACT UP, one (male) individual activist, and one woman living with HIV who has been featured in the Department of Health’s “HIV Stops with Me” campaign. Out of the seven of us in the group, I believe only two of us (myself included) were HIV-negative. In preparation for lobbying, we had been given folders with information on the current state of the epidemic in New York State, the Ending the Epidemic goal of reaching 750 new infections per year by 2020 along with the major legislative “asks” from the End AIDS NY 2020 coalition (aligned with the Blueprint), and a document drafted by coalition members that outlined Ending the Epidemic recommendations for the 2016 state budget. Although we divided up the talking points ahead of time, much of the first lobbying visit involved several group members telling their personal stories of accessing, or having trouble accessing, services from the state, and what this has meant to them. For example, Gina had specifically been chosen to join this group because she lives in Yonkers and we were meeting with legislators from Westchester. Gina, who is debilitated due to HIV and laryngeal cancer, talked about how she is not able to access housing assistance through

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10 For ethical reasons, both during the course of this research and in other work I have done in the HIV/AIDS field, I never inquire whether a person is HIV-positive. Instead, I only make note if they are public about their status and make an effort to identify my own HIV-negative status where appropriate.
HASA, because she lives just outside the New York City border. This story aligned with one of the legislative “asks” in our packet to expand HASA throughout the state.

Ultimately, the Legislative Education Day highlighted the ways in which contemporary AIDS activism still relies on models of mass mobilization, individual testimonials (Nguyen 2002), and a deference to authoritative knowledge like the statistics we were prompted to cite when talking with legislators. Yet, the significant representation from communities of color organized by VOCAL-NY and Tracie Gardner’s reference to the assembled activists as her “family” also point to AIDS activism’s changing face. It no longer takes a group of gay white men to draw a crowd of activists; in fact, groups like ACT UP now have less ability to mobilize en masse than groups like VOCAL-NY that draw from communities of color. At the same time, longstanding activists like Tracie Gardner, Dan Tietz, and Demetre Daskalakis now work for state and city government, bringing their activist and “family” ties with them.

Launching the Blueprint: A Symbolic Moment

On April 29, 2015, Governor Andrew Cuomo stood in front of The LGBT Center in New York City’s West Village and publicly accepted the Blueprint. West 13th Street had been blocked off for the occasion, and a stage was set up in front of The Center with a small fenced-off area in front for Task Force members and AIDS Institute employees. Prior to the event, activists with participating organizations like Housing Works, VOCAL-NY, GMHC, and Harlem United had marched in on both sides of the street carrying placards, and I stood with the activists packed in around the fence. The governor was introduced by Charles King, whose acknowledgment of Mario Cuomo’s work to found the AIDS Institute was reminiscent of his closing Task Force speech and brought tears to the governor’s eyes. The governor then took the stage, announcing

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11 Formerly the director of ACRIA, now working with the NYC Human Resources Administration.
his support for the Blueprint and noting that New York has already blazed a trail in other areas, such as passing marriage equality. Echoing activists’ claims that New York is poised to make history, Cuomo said that the state will lead with ending AIDS, and consequently "every state and every community has the obligation" to end the epidemic as well.

Similar to the March 11th Legislative Education Day, representatives of different constituencies took the stage one at a time once the governor had made his exit. At this point the crowd was dwindling, but perhaps the most poignant moments of the day took place toward the end of the event. When Mark Harrington took the stage, he noted that he was wearing his former lover’s shirt. Mark told the assembled group that he originally moved to New York City to be with his lover, who ended up dying of AIDS in the 1990s. At this point, I heard a loud sob and looked over to see one of ACT UP’s original members crying with a hand over his face. The emotion of the moment was stunning; the symbolism Mark was calling on by wearing his former lover’s shirt, as though calling upon his presence at what Charles King has called “the beginning of the end of AIDS.” At the same time, the ACT UP member’s inability to control his own emotions further underscored how deeply significant this day was for those who have been in the field for a long time.

Yet, when Mark began to talk about PrEP, Carrie, a transgender sex worker of color I had recently met at an unrelated event, stood up in front of the podium and loudly asked “What about PEP?,” asserting that PrEP hasn’t even been proven effective. At this point an ACT UP member, a young gay white man who has become well known in activist circles for his work around PrEP, began shouting back at her from across the fence. While Mark eventually was able to quiet the argument and finish his speech, the shouting resumed after the event concluded, with ACT UP members on one side of the fence and a small group of transgender sex workers on the other.
Even at the time I was struck by the symbolism of the moment in the context of the history of AIDS activism; a group of educated gay white men literally on one side of a fence while a small group of transgender sex workers of color shouted at them from the other side.

**Discussion & Conclusions**

The early days of the Ending the Epidemic campaign demonstrate how AIDS activists work together amongst themselves and also how they work together with state government toward an ambitious shared goal, thereby institutionalizing both the outcomes of the Task Force and its internal politics. While many Task Force members felt that their goal was ultimately to use Ending the Epidemic to fix larger social disparities, the question remains as to whether or not the Task Force itself realized these principles both and in practice and in the final document, the Blueprint, they produced.

On the one hand, more established activists went about building the movement using the strategic acumen, professional status, and thorough knowledge as “lay experts” (Epstein 1995) that they have built up over decades in the field. As a result, they were successful in garnering buy-in from both the governor’s office and from the AIDS Institute, and several of these activists held prominent places on the Task Force, where they continued to hold a certain amount of power. However, the politics of the EtE Task Force and Blueprint launch process provide a more complex picture of what AIDS activism looks like today and what it takes to both produce and mobilize a policy document.

Internal conflicts on the Task Force reflected ongoing struggles around racial politics, as well as around the extent to which a range of activists are willing to “play the game” in politics to achieve their goals. Indeed, change comes with many growing pains. For example, Stephanie’s late addition to the Task Force and Damian’s role as the sole young MSM of color.
However, it is noteworthy that when Damian raised concerns about underrepresentation in the Blueprint, these concerns were taken seriously and addressed. In addition to Damian’s role as a sub-committee co-chair, this development suggests that his role on the Task Force was actually meaningful and was not just a tokenistic attempt to symbolically include a young HIV-positive MSM of color. And as a result of these kinds of conflicts, the final Blueprint included more inclusive language and addressed a broader range of concerns that it otherwise would have.

At the same time, while external organizing among activists relied heavily on tactics pulled from the early days of AIDS activism, such as public mass mobilization and testimonials, this organizing was particularly noteworthy for its heavy reliance on communities of color to turn out the numbers that majority white, male groups like ACT UP could once mobilize. So, while the ability to work closely with government is still constrained by the privileges of race, class, and gender that have long characterized the movement, this is clearly changing. It is true that the movement has long relied on identity politics, cut contemporary AIDS activism needs communities of color in particular to create the sense of spectacle and urgency that has been integral to garnering attention and resources in the past.
CHAPTER 2 The Implementation Phase: What Is “Community” and What Does It Do?

On Halloween Day 2015, the National Black Leadership Commission on AIDS (NBLCA) and the National Action Network (NAN)\(^\text{12}\) held an Ending the Epidemic town hall at the NAN House of Justice, a storefront on 145th St. a couple of blocks from the entrance to the RFK bridge. As I approached the building, I saw two mobile testing vans parked outside and some representatives on the street offering passersby free HIV tests. Just down the street, I noticed a woman in a wheelchair; she was missing a leg and the lower half of her body was loosely covered with a white sheet and nothing else. The woman was smoking and I smelled crack coming from her direction. As I entered the meeting, I thought how ironic and also symbolic it was that a woman who fit most of the campaign’s descriptions of a “key population” was only about 50 feet away from the testing vans, and yet she was untouched by the efforts.

If, as described in Chapter 1, Ending the Epidemic ultimately aims to address social disparities through the lens of HIV/AIDS, how is this goal accomplished in practice? How do EtE participants go about bridging the proverbial gap between the woman on the corner of 145th Street and those inside the NAN House of Justice? Building on the concept of identity politics outlined in the Introduction, AIDS activism’s answer to this question historically has been to appeal and reach out to “community” to bridge these gaps. Yet, this concept is nebulous and its limitations have long gone unrecognized.

In anthropology, we often trace the concept of “community” back to Ferdinand Tönnies and his distinction between *Gemeinschaft* (translated as “community”) and *Gesellschaft* (translated as “society”). According to Tönnies, communal relations are organic, direct, and

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\(^{12}\) A civil rights advocacy organization founded by Reverend Al Sharpton.
sentimental, while societal relations are indirect and rational, being structured and mediated by governmental and industrial bureaucracy ([1887] 1957). Williams ([1976] 1985) defines “community” as both a “sense of direct common concern” and “the materialization of various forms of common organization” (Ibid.:76). Similar to Tönnies’ juxtaposition of community and society, Williams suggests that the concept of community is “warmly positive” and so is often used with positive connotations, as opposed to concepts like “state” or “society” (Ibid.). However, Creed (2006) points out that the concept of community has mobilizing power, which ranges from “challenging systems of oppression to provoking communitarian violence and genocide” (Ibid.:2). Indeed, Kanter (1968) has noted that creating commitment to “community” can involve mechanisms of social control. Community is not just warmly positive, as Williams suggests, but much more complex. As Creed notes, “…collectivity and exclusion are two sides of the same coin, and to understand either, we need to look at them together – community is the coinage” (2006:2).

AIDS activism has long drawn on the concept of community, with the underlying implication that this concept is “warmly positive” as Williams suggests. Early AIDS activism relied heavily on gay identity politics at a time when being gay was far less socially acceptable than it is today, necessitating communal bonds and mobilization among gay men who otherwise felt persecuted (Hodge 2000; Gamson 1989). And it was this activism that resulted in greater inclusion of PLHA into governmental processes, such as reviewing and developing research protocols with the FDA (Crimp 2011). Indeed, one of AIDS activism’s hallmarks is this standard of community participation, which has even been enshrined in global HIV/AIDS policy through principles like the “Greater Involvement of People Living with HIV/AIDS” (GIPA) (Magaz and Hardee 2004; Stephens 2004; Van Roey 1999), and is evident in the open access “Global
“Village” that runs alongside the (relatively expensive and exclusive) biannual International AIDS Conference. Following this trend, the Ending the Epidemic Blueprint includes a section at the beginning titled “Community Leadership and Engagement” (New York State Department of Health AIDS Institute 2015:9-10), which seems to be an attempt to claim legitimacy for the document in a field where involving the community has become a requirement.

As Parker (1996) notes, community mobilization has become increasingly important in the HIV/AIDS field as it has shifted from blaming individuals for risky behavior to mobilizing patients as a community to advocate for themselves. But, following Creed, “…collectivity and exclusion are two sides of the same coin” (2006:2). While anthropologists have pointed to the intersections of race, ethnicity, gender, and class as key determinants of HIV risk (Baer, Singer & Susser 2013; Farmer 2006), scholars also recognize that mobilization around certain communities in AIDS activism has led to the exclusion of others, such as women (Elbaz 2003) and people of color (Gould 2012). And Patton (1990) has noted the tension in AIDS activism between the requirement that “communities” mobilize around particular identities while at the same time having to delink these identities from particular sexual practices to gain legitimacy. Community participation is important for AIDS activism and in most respects it is a good and necessary thing, but what about the other side of the coin? Where and how are certain people excluded in communal efforts?

In the case of Ending the Epidemic, concepts of community and of working together often jut up against mandates around individual responsibility that characterize the neoliberal turn in healthcare. Scholars have pointed to the strong relationship between globalization, associated neoliberal policies, and the spread of HIV/AIDS (Baer et al. 2013; Susser 2009). And indeed, HIV/AIDS continues to spread as health systems become increasingly neoliberalized
(Larsen and Stone 2015; Davis 2009; Navarro 2007), which is indicated by a “hyper-individualized, free-market, consumerist set of politics that are deployed at the state level” (Maskovsky 2000:123). In this context, policy makers increasingly are calling on patients to take greater personal responsibility for their health (Metzl and Kirkland 2010) and attempting to decentralize healthcare management to providers (see, for example, a proposal from Ham and Alderwick 2015). AIDS activism, and consequently healthcare for people living with HIV and AIDS (PLHA), has developed in such a way that it depends heavily on the state for resources such as Medicaid funding (Graydon 2000) while simultaneously encouraging patients to advocate for themselves and referring to patients in the neoliberal language of “consumers” (Rosengarten 2004; Gould 1989). In particular, while a focus on “community-based” interventions and “community-based” organizing has been relatively successful in the HIV/AIDS response, this focus simultaneously sends the message that a community is responsible for its own. Indeed, Ending the Epidemic organizers suggest that “Together, we can end AIDS” while also calling on individuals to do their part.

Drawing on data gathered during the first eight months (May – December 2015) of EtE implementation, this chapter examines how community is constituted and used as the campaign is realized on the ground. What happens as a neoliberal healthcare system increasingly turns to community-like concepts such as “collaboration” to realize its goals? On the one hand, engaging

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13 Deber et al. (2005) note that this language is based in bioethical and legal standards that call for patient autonomy and participation in care. This framework complicates a strictly negative association between the patient “consumer” and neoliberal healthcare. However, Deber et al. also note, “the terminology of ‘consumer’, ‘customer’ and ‘client’ can be seen as carrying potentially more objectionable overtones, to the extent that they imply that medical services are commodities to be managed in a market. Implicit in consumerism is that the consumer is the sole arbiter of his or her needs, and that the role of the tradesman is to satisfy them” (Ibid.: 346) rather than guiding a patient to the best possible health outcome. This is one of the reasons why the term “patient” often is preferred to “consumer” or “client.”
community is integral to the success of such a massive initiative. On the other hand, in the context of a healthcare system that encourages providers to do more work and take more responsibility with fewer resources, it is possible to ask too much of communities that already are stretched too thin and may reinforce existing lines of inequality.

**The Mandate to Collaborate**

*Medicaid Reform & DSRIP*

As many of those involved in Ending the Epidemic recognize, this campaign is not entirely new, but is “building upon decades’ worth of work.” As a result, it is difficult to differentiate a clear beginning to EtE implementation and it has certainly tapped into a number of ongoing initiatives, as indicated by the extensive 2015 – 2016 activity report posted to the AIDS Institute’s Ending the Epidemic website (New York State Department of Health AIDS Institute 2016). Perhaps the largest and most influential state-level initiative that Ending the Epidemic organizers are attempting to tap into is New York’s Medicaid redesign. Under provisions from the Affordable Care Act, New York has expanded Medicaid eligibility throughout the state and embarked on a five-year reform plan. According to an action plan published by the Department of Health, Medicaid redesign is meant to create “a national model for cost-effective health care delivery” (New York State Department of Health n.d.: 5). This means that, while Medicaid has long relied on a “disparate network of service providers…These providers must be supported in a process of transformation to become a true coordinated ‘system’ which provides evidence-based interventions that are proven to be effective” (Ibid.: 9). The plan notes that this “approach to improving population health is built on its years of experience in other areas, such as the fight against AIDS” (Ibid.: 21).
There are a few different mechanisms through which the state’s Medicaid Redesign Team (MRT) has proposed to accomplish this coordinated system. One of these is the creation of “health homes” as outlined by the Affordable Care Act. Health homes are essentially a means of coordinating service providers to work with people who have complex health needs through “forming new partnerships and stretching their list of services…” (Ibid.: 13). Similarly, Medicaid redesign draws on the concept of Medicare Accountable Care Organizations, which according to the Centers for Medicare and Medicaid Services website, bring providers together “voluntarily to give coordinated high quality care…” In an interview with Charles King, he was very enthusiastic about the ACO concept and told me he has been advocating for a state-wide ACO for HIV/AIDS. According to Mr. King, an ACO is a network of providers that comes together and assumes full risk-bearing responsibility for cost of care. He likens this to an insurance company where providers assume responsibility for the health outcomes of their selected service population.\(^\text{14}\) Mr. King also noted in our interview that Amida Care, an insurance plan meant for PLHA, is moving toward becoming a state-wide ACO. According to the organization’s website, Amida Care was founded by several community-based AIDS service organizations in New York City, including Housing Works and Harlem United. Amida Care’s current CEO also served on the EtE Task Force.

Another highly influential piece of New York State Medicaid reform is the Delivery System Reform Incentive Program (DSRIP). DSRIP is a five-year process of re-investing

\(^{14}\) As a relatively new concept under the Affordable Care Act, the jury is still out as to whether ACOs ultimately will both reduce cost and improve patient health outcomes (Burke 2011). On the one hand, because many Medicare patients receive care from systems that are already relatively coordinated at the local level, the ACO concept might just be a means of formalizing this model (Fisher et al. 2007). However, some scholars point to concerns that they could ultimately focus more on the goal of slowing spending growth than on patient care, or could demand unreasonable prices as they become more powerful through integration (Fisher and Shortell 2010).
savings generated by the MRT reforms into the Medicaid system. According to the Department of Health’s website:

The DSRIP program will promote community-level collaborations and focus on system reform, specifically a goal to achieve a 25 percent reduction in avoidable hospital use over five years. Safety net providers will be required to collaborate to implement innovative projects focusing on system transformation, clinical improvement and population health improvement. Single providers will be ineligible to apply. All DSRIP funds will be based on performance linked to achievement of project milestones. (New York State Department of Health 2016; emphasis my own)

During a presentation to the AIDS Advisory Council (see below) on DSRIP, a representative from the accounting firm hired to work with the Department of Health on Medicaid redesign similarly referred to DSRIP as a “more integrated and more community-based” model. So, one way that Medicaid goals are achieved is through requirements for participating providers. Under the DSRIP guidelines, providers must commit to implementing at least five quality improvement projects from a designated list that includes projects to transform local health systems, clinic-based projects, and population-wide projects (New York State Department of Health n.d.). In addition, according to the DSRIP website, providers must participate in DSRIP learning collaboratives to exchange ideas amongst themselves. Thus, New York State’s Medicaid redesign process appears to rely in part on service providers taking on more responsibility for their patients’ health outcomes, both individually and within local networks and collaborative groups. Further, at a July 2015 EtE Blueprint implementation event held in New York City, a representative from the Department of Health suggested that DSRIP also involves “engaging” patients and getting them “activated” around health behaviors. This comment suggests that patients, too, are being encouraged to take individual responsibility for their healthcare.

The Medicaid redesign process therefore aims to minimize divisions among providers and create more cohesive local health systems by requiring participating providers to work
simultaneously alone (on individual projects) and together in collaborative groups. This process sends a message of both individual and collective responsibility, even among patients, which is ultimately meant to create a “more integrated and more community-based” model of healthcare.

*EtE Regional Implementation Meetings*

Through its Office of Planning and Community Affairs, the AIDS Institute has played a central role in organizing and administering to the Ending the Epidemic campaign. One of the AI’s most notable activities early in the implementation phase of the campaign was to coordinate and conduct 14 regional discussion meetings (including one Spanish-language meeting in New York City) across the state to launch the Blueprint at the local level. I was able to attend seven of these meetings: five in New York City (Upper and Lower Manhattan, Brooklyn, Queens, and Staten Island), as well as two in Western New York (Buffalo and Rochester) in my role as qualitative evaluation researcher for NY Connects. Typically, the meetings featured welcome addresses from high-level AIDS Institute staff and local dignitaries, such as a borough president in New York City or a local health commissioner. Participants would then discuss regional needs and best practices as a whole group before breaking into small groups to identify priority Blueprint recommendations and develop plans to apply these recommendations locally. While priority issues and strategies differed a bit among the regions, I found that participants regularly brought up concerns around funding and around provider education, in addition to questions around addressing “key” populations.

At these meetings I noted that providers seemed eager to work together if called on to do so by EtE. However, this was partly a response to “competition” for limited funding in a resource-constrained environment, which providers seem to believe they can overcome through increased “collaboration”; a buzzword that features prominently in the EtE campaign. As one
participant at the Brooklyn implementation meeting noted, the group needs to work toward “true collaboration” and reducing “competition” while another participant at the Rochester meeting called on attendees to “step out of our silos” and work on “collaborating.” Indeed, collaboration is particularly important when it comes to accessing funding, since new programs like DSRIP require that providers work together in order to receive money.

This mandate to collaborate juts up against consistent messaging around individual responsibility for EtE outcomes that often comes from Charles King. At several meetings, Charles discussed the importance of viral load suppression in achieving the end of the epidemic, saying that programs focusing on viral load suppression can be successful “When everybody owns the responsibility” and “It requires that every single one of us own the responsibility for viral load suppression… it used to be the doctor’s job… it is now everyone’s job.” Similarly, Charles would close the meetings with an appeal to all present to do their part in ending the epidemic, saying something like, “There’s only one way we can end the epidemic, and that’s through you. You are the tool that’s gonna get us through to the end.” While these kinds of appeals rarely drew any protest, at one point during the Rochester implementation meeting a man (presumably a person living with HIV/AIDS) stood up and protested that the state is increasingly turning to PLHA to take “responsibility” for themselves, rather than providing the assistance it used to provide in the early days of AIDS: “That hand is being withdrawn and I don’t think we’re being put in a position to take responsibility.”

*NY Connects*

New York Connects (NY Connects) is another example of a long-running state effort that has been brought under the EtE umbrella, and which simultaneously sends a message of collaboration and individual responsibility. NY Connects began in 2011 with the goal of bringing
HIV/AIDS service providers into regional collaborative groups to improve linkage to and retention in care through quality improvement projects. The NY Connects mission later expanded to improve viral load suppression rates as well. NY Connects collects data on linkage, retention, and viral load suppression from each participating provider site on a monthly basis and then turns these “treatment cascades” around to the sites, which are encouraged to use the data for their own internal quality improvement. HIV treatment cascades, also called “care continuums,” are visualizations of provider site performance that are meant to show the dynamics of care at a given organization, which can then be combined together to create a visualization of population-level care. The cascades show the progression of the total number of patients diagnosed with HIV through linkage to and retention in care, adherence to antiretroviral therapy, and viral suppression (Kay et al. 2016). In an ideal world, all of the patients diagnosed with HIV are then linked to care, retained, stay on treatment, and ultimately are virally suppressed. However, the cascades generally show decreasing numbers of patients at each phase, providing a visualization of gaps where providers can step in to help their patients make it to the next step. By generating both facility-level and region-wide cascades, which are frequently discussed in meetings with providers, NY Connects sends the message that it is each individual site’s responsibility to see their own patients through the full cascade, but also that providers should work in concert to improve population-level outcomes for their region and the state.

While NY Connects originally was conceived as a five-year program funded by a grant from the U.S. Health Resources and Services Administration, the initiative continued to grow and to add new regional groups into 2016. Beginning with regional collaborative groups in Upper Manhattan, Western New York, and Queens and Staten Island, NY Connects has expanded to cover most of the state. The original idea behind NY Connects was to build regional
groups using technical advisory consultants through the AIDS Institute, and then to hand leadership of the groups over to local providers over time (ostensibly, the initial five-year grant period). However, this goal has produced mixed results so far and in 2016 Western New York appeared to be the only region where the group was largely self-functioning. The relative success of one branch of the Western New York regional group in Monroe County (Rochester) provides one of the most striking examples of integration with EtE and of community collaboration: Monroe County Partnering to End the Epidemic (McPETE).

Under McPETE, providers in Monroe County have put protocols in place to share patients amongst themselves to increase linkage to and retention in care. For example, the group developed the “Crisis Captain” model in which a patient newly diagnosed by the Monroe County Department of Public Health (MCDPH) could be directly handed off to the day’s designated “crisis captain” (a shared responsibility among local providers according to a set rotation) in order to immediately enroll the patient in care and minimize the risk of losing them to follow-up.

Recounting the story of how McPETE began, Whitney, a representative from the MCDPH, said that prior to joining NY Connects in 2012:

…we had partnerships with many of the agencies within the Monroe County community. However…they were pretty much standard form MOUs [memoranda of understanding]. Very general…being part of McPETE and seeing all of our partners together in one room really enhanced and really made us think about the way we need to reach out to our partners in order to better serve our Monroe County residents…as we began to create more meaningful partnerships, because what New York [Connects] did is it brought everyone together with a shared objective. So, with that in mind Monroe County began reaching out to different agencies looking at what their unique strengths were and looking at the work that we are in charge of doing as a county and we began to reach out and partner to create these relationships that really enhanced linkage and retention…So, when NY [Connects] ended, it ended with all of us partners still very active. Many of our partners had created their own individual interventions and so we felt like coming together to end the epidemic, continuing our partnerships and building off those existing interventions and relationships that we built around NY [Connects]. We met, decided to continue our work…came up with McPETE.
Here, Whitney traces the organizing around Ending the Epidemic back to the county’s involvement with NY Connects and then notes that the EtE campaign provided a framework through which to continue these efforts as NY Connects was winding down. However, she goes on to describe exactly how the transition from NY Connects to McPETE took place. Noting that attendees at the final Western New York regional meeting were encouraged to continue NY Connects work under local leadership, she said the group started to consider different ways to do this:

So, we started thinking about well, ending the epidemic, or just meeting to continue our partnership. We weren’t sure, but we knew that we wanted to meet to discuss something. So, right after that meeting…we got this notice that New York State was coming out and they were doing these “road shows” [the regional implementation meetings] if you will. They were traveling to each region and putting out this end of the epidemic action plan. So, listening to that action plan, knowing the group that we had already started. All of our minds were like ticking and we were like “Wow, this is really what we’re doing. Ending the epidemic.”

So, the group began to meet and continued to draw from its NY Connects experience to inform new participation with ETE. When designing McPETE’s objectives, for example, Whitney said:

…all of our objectives needed to be measurable…So, we looked back to NY [Connects]…[we were] already reporting [data] to NY [Connects]…much of what was reported to NY [Connects]…fit along the lines of the EtE…So, we said, wow, we’ll make these objectives…[and in addition] two new objectives…re-engagement, because New York State has also put together its pilot of Expanding Partner Services…those numbers are so high we cannot ignore that…And then PrEP, we all know that PrEP and PEP, those are hot topics…[and] under-utilized…it just made sense…

Here, she notes the fit between NY Connects objectives and the objectives set out by EtE, which made for a smoother transition from one initiative to the next. However, at the time I spoke with Whitney the relationship between McPETE and the EtE regional steering committee appointed by the AIDS Institute remained unclear. While the steering committee was appointed at the Monroe County regional implementation meeting, McPETE developed independently and when
I interviewed Whitney in late 2015, she thought that the regional steering committee had not yet
held a formal meeting. She expressed concern about this disconnect, saying:

…our greatest fear is that we would have done all of this work only for the regional team
to say “This is what we’re doing” and then have folks drop off from McPETE to join the
regional group. Because there may be some duplication…

So, the McPETE group was concerned that they are out of the loop regarding larger regional EtE
efforts, and therefore may be duplicating other work by continuing to meet independently.

Ultimately, NY Connects holds up the McPETE case as a story of successful community
collaboration, and this model has been subsumed under EtE. However, while McPETE was
originally inspired by NY Connects, it seems to privilege a community response and population-
level change over improvements made at individual provider sites. The NY Connects model of
individual sites taking responsibility in order to improve the whole therefore doesn’t quite fit.
The McPETE story seems more to be one of simply working together.

Further, Whitney’s confusion about the role of McPETE versus the role of EtE is telling.
When individual partners are being called on to collaborate in multiple overlapping realms
(indeed, many of the most influential providers in NY Connects reported participating in several
state- or region-wide networks at once), which takes precedence and how do providers choose?
In some cases, state funding depends on participating in certain initiatives, which takes away any
element of choice at all, in which cases providers feel they are mandated to collaborate.

*Informed NY*

An example from an HIV testing initiative run by New York City’s Department of Health
and Mental Hygiene (DOHMH) provides an informative counterpoint to NY Connects and
McPETE. Informed NY is a campaign that has been running across New York City, expanding
borough-by-borough, for almost 10 years. The most recent addition to Informed NY is a Manhattan working group, and I was able to join some of their early meetings in 2015.

Similar to NY Connects, Informed NY requires regular data submissions from members in order to track borough-specific progress on measures of HIV testing and linkage to care. In contrast to NY Connects, Informed NY participants meet monthly and meetings are jointly run by the Informed NY project officer from DOHMH and two community co-chairs (whereas NY Connects meetings have historically been led only by AIDS Institute staff). Having attended a number of NY Connects meetings, I was struck by the variety of participants in the room at the initiative’s first in-person meeting in November 2015. While NY Connects focuses on direct health service providers, the Informed NY group included members of ACT UP as well as representatives from legal services and a church in Harlem. A couple of prominent pharmacy chains also have agreed to work in partnership with NY Knows to promote HIV testing days in their pharmacies, suggesting that the NY Knows “community” is wide-ranging.

Still, as with Whitney’s concerns about participating in both McPETE and in EtE, at the November 2015 meeting one participant expressed confusion around what it means to be a member of Informed NY and the difference between this initiative and others such as EtE and NY Connects. He also expressed concern that some of these efforts are redundant. The DOHMH project officer in charge of the initiative discussed how EtE, NY Connects, and Informed NY are really all part of a “collaborative national effort” to work toward the goals of the National AIDS Strategy. A representative from NY Connects then stood up and said that ETE is an “umbrella” for work that is already happening, not a “separate silo.” So, NY Connects and Knows should be a “natural fit,” because people who are repeat testers are likely not linked to care.
However, the Informed NY message is different from NY Connects insofar as it seems to focus solely on population-level change as opposed to focusing on individual providers. While Informed NY asks member sites to submit data, at the meetings I attended in 2015 it appeared that these numbers were only used to provide a borough-wide picture of HIV testing; the DOHMH project officer noted the numbers were for “assessing how we’re collectively doing.” Between this use of data, the range of participants involved in Informed NY, and the community co-chairs who run the group with a government project officer, Informed NY presents a different picture of community engagement and its ultimate goals than the picture presented by NY Connects. The Informed NY net is much wider and its goals more heavily skewed toward population-level change through a concentrated collective effort. While NY Connects has certainly made attempts to generate real collaborative efforts, the message it sends can be confusing to providers who seem to be held more accountable for their individual numbers, which are then expected to add up to change at the level of the region and the state.

Perhaps because of this clarity and the call to work together, NY Knows participants seem enthusiastic over all. The DOHMH project officer has told me that a sub-committee on youth issues that was proposed at the first meeting is now meeting regularly, along with sub-committees on prevention and event planning. The DOHMH itself appears to function largely as an organizing force that also disseminates information, sending out a weekly digest to all partners that includes upcoming events and initiatives sponsored by “community partners” (a term used often by DOHMH staff) as well as job postings.

Section Summary

In summary, government-led processes related to Ending the Epidemic implementation seem to send a message of what one NY Connects member called “collective individualism”: 
EtE participants are charged with individual responsibility for themselves and/or their patients, as well as the responsibility to “collaborate” and work toward the greater goals of ending the epidemic in their region. For some, taking on those responsibilities has been relatively seamless. In Monroe County, the existence of NY Connects as a pre-EtE framework, as well as the county health department’s ability to draw on personnel and resources from the AIDS Institute facilitated the uptake of EtE objectives in a new regional collaborative group. On the other hand, PLHA at the EtE regional implementation meetings have complained that they are being encouraged to take responsibility for their own health without receiving adequate resources to do so. This view offers a contrast between providers who literally receive resources from the state to encourage collaboration and patients who don’t feel they receive enough support to care for themselves.

In contrast to state-run initiatives like NY Connects, which are being pulled into Ending the Epidemic as part of the campaign’s programatics, Informed NY appears to cast a wider net in terms of who is invited to join the initiative and become one of the Informed NY “community partners.” Similar to NY Connects, by requiring regular data submission and tracking HIV testing progress for the borough as a whole, NY Knows sends the message that everyone involved is responsible for working together to improve HIV testing and linkage to care, and there is far less emphasis on individual responsibility here.

**Gendering Community Participation**

While above I discussed the way that concepts of “community” and “collaboration” are used to mobilize participants in Ending the Epidemic, here I turn to the way community is constituted and the power dynamics involved. If this dissertation examines longstanding inequalities in AIDS activism, it became clear to me during the early EtE implementation phase
that inequalities along the lines of gender remain largely unchanged. Interestingly enough, the
campaign makes clear attempts to include transgender people (mostly transgender women) in
publications and panels, but cisgender women continue to occupy an awkward place where they
may have differential access to power according to their race and class, but their gender puts
them in a lesser position than men.

*The AIDS Advisory Council*

While high-level government processes often are slow, Ending the Epidemic
implementation work from the level of the AIDS Institute down to the ground progressed
rapidly. Even before the Ending the Epidemic Task Force officially disbanded in January 2015,
the organizers had already devised a mechanism to oversee the Blueprint’s implementation. This
mechanism is an Ending the Epidemic sub-committee of the AIDS Advisory Council (AAC); a
standing body created by statute that is meant to advise the Commissioner of Health and the
AIDS Institute. The sub-committee is co-chaired by the current AAC chair (Dr. Marjorie Hill, a
woman of color who is CEO of a family health center in Queens) and by Charles King. In an
attempt to draw continuity from the Task Force to the AAC, the sub-committee membership was
drawn from the original Task Force. Since the larger AAC is meant to act as a liaison between
activists and providers and the State Department of Health, the EtE sub-committee organizes and
develops input around policies and programming related to EtE, and feeds this back to the larger
AAC through members like Dr. Hill who serve in both realms. Since AAC sub-committee
meetings are open to the public, they serve as a venue to provide “community” updates regarding
ETE progress and non-AAC members regularly attend in person or call in. So, it basically
functions as another link between community and government specifically meant to feed into the
Ending the Epidemic process.
Early on, representation on the AAC sub-committee became contentious. While the EtE Task Force sub-committee co-chairs were asked for individual recommendations for the AAC sub-committee, some were confused by this process and controversy arose. According to Charles King at the AAC sub-committee’s first meeting in February 2015, the Task Force was charged with setting up a “democratic, transparent” process to elect representatives to the AAC. However, Charles noted, “there’s been more than a little discussion” about how this was actually done. This conversation clearly struck a chord with the sub-committee members and launched a passionate conversation, although during the several subsequent meetings I attended it was never clear to me that this issue was more fully addressed.

Even if sub-committee membership did not become an ongoing conversation, the general issue of equal representation came up regularly in the AAC sub-committee to varied effect. One moment that stood out to me occurred during a discussion of PrEP at the September 2015 meeting. One member, Emily, observed that “cisgender women are completely erased” in most conversations about PrEP. So, she wondered where this population falls in a discussion of target populations? Charles King responded to this question by saying that the group was running out of time and suggested taking the conversation offline, but then proceeded to open up the conversation to general questions. Essentially, it appeared as though Emily’s question was dismissed.

EtE Regional Implementation Meetings

According to Aultman (2014) this term “can be used to describe individuals who possess, from birth and into adulthood, the male or female reproductive organs (sex) typical of the social category of man or woman (gender) to which that individual was assigned at birth. Hence a cisgender person’s gender is on the same side as their birth-assigned sex, in contrast to which a trans-gender person’s gender is on the other side (trans-) of their birth-assigned sex” (61). The term derives from trans activism of the 1990s that aimed to question the normalization of cisgender identity.
All of the regional implementation meetings were co-chaired by Charles King and a staff member from the AIDS Institute, usually Johanne Morne, who was head of the Office of Planning and Community Affairs at the time. Meetings would close with Charles King calling out one member in the group to stand up and agree to chair a regional implementation committee (a practice that usually went smoothly, but caused palpable tension in the room during a meeting at which the “volunteer” had not been notified ahead of time) before asking others to stand up and offer to join the committee. At the end of one such meeting in Queens, when Charles King asked for volunteers to join the regional implementation steering committee, only women stood up. This prompted Charles to say “any men?” and to joke “Be a man about it…Man up.”

Indeed, while implementation meeting participants were eager to discuss strategies for engaging “hard to reach” or “key” populations, they often focused on who was missing from the room as opposed to who was present. In my experience at these meetings, women (particularly women of color) tended to be over-represented both in the audience and among AIDS Institute staff who were facilitating. At the Queens implementation meeting, for example, I sat in on a small group discussion that was facilitated by a woman staff person from the AIDS Institute and the group contained only one man. At this level, then, women, and particularly women of color, are almost overrepresented.

To be sure, Johanne Morne was promoted to Director of the AIDS Institute once Dan O’Connell stepped down in 2016 and the AAC sub-committee is co-chaired by a woman of color. However, it is notable that in these spaces one woman, Emily, was silenced when she tried to speak out on behalf of women who use PrEP. And at the same time, the only ones willing and able to coordinate community-level work for EtE were women. While some women may have
more of a voice than they used to in AIDS activism, clearly old power differentials remain when women are doing the work on the ground, but men often remain in charge of the overall vision.

**Mobilizing Community to End the Epidemic: Young People Left Behind**

In addition to the formal regional implementation meetings that the AIDS Institute hosted across the state, some activist groups also organized their own events to introduce their respective constituents to the Blueprint. The most prominent of these was the July 2015 “Ending AIDS 2020: Blueprint to Action” event organized by a group of activists that initially called themselves the EtE “community stakeholders.” The event was co-sponsored by major funders such as the MAC AIDS Fund and the Elton John AIDS Foundation, and was held in an airy, light-filled space overlooking the World Trade Center at the New York Academy of Sciences with catered breakfast and lunch. The day-long agenda included sessions on measuring progress toward ending the epidemic, funding the plan, mobilizing for implementation, and working with populations most at risk for HIV. Panelists ranged from AIDS Institute staff to a representative from Governor Cuomo’s office to current PrEP patients.

During the course of the day, attendees seemed particularly interested in discussing the needs of “key populations” and their representation within Ending the Epidemic planning frameworks. At one point, a transgender woman in the audience stood up and discussed some of the factors that affect her health, such as difficulties finding employment despite being well educated. Expressing her frustration, she concluded with “I feel like my viral load has gone up just from sitting in these meetings.” Later, following a data presentation from the NYC DOHMH, an audience member asked if the city had data on trans people, which the presenter responded was available for the past 10 years, but she felt she didn’t have time to present this. Audience members expressed their displeasure at this exclusion and called for more data.
transparency around trans populations and the importance of including trans people on research committees. As another trans activist said, “[it’s] not just what you can do for us, but what we can do for you.”

Men who have sex with men (MSM), particularly MSM of color, are another “key” population that is a focus of EtE efforts, and the event featured a panel discussion titled “MSM and Transgender People of Color – What works for populations at risk?” during which two MSM of color (the transgender panelist was delayed and joined another panel later in the day) discussed their challenges protecting themselves from HIV (through accessing PrEP) and accessing supportive services to stay on HIV treatment. While trans activists were a vocal presence at this event and MSM of color also received attention on the agenda, a couple of other people in the room quietly expressed feeling excluded. As one man said at the end of the panel on key populations, “It’s awkward for me as a straight black male to feel excluded” in this kind of conversation, although his comment didn’t provoke further discussion. Following the event, I also spoke privately with a young woman of color who I had seen approach the microphone several times with a question only to have her questions un-answered when older activists spoke up first. As someone who is young herself and who provides sex education to other young people, she told me after the event that her question had been around addressing the needs of young people in the campaign. It seemed symbolic to me that, as perhaps one of a handful of young people in the room (if that), her question was constantly overshadowed.

Similarly, young people didn’t appear to be an active part of the conversation at a World AIDS Day event held at The Apollo Theater in Harlem in December 2015. This event was co-sponsored by 60 organizations from across the city identifying themselves as the “End AIDS NY
2020” coalition. The audience at World AIDS Day more than filled the historic theater, and featured speakers included both Governor Cuomo and New York City Mayor Bill de Blasio in addition to numerous City Council representatives, activists, and a former contestant on RuPaul’s Drag Race. While the event was scheduled to last two hours, it ultimately took closer to three. This is likely because both Governor Cuomo and Mayor de Blasio had not been included on the program (it is likely that they confirmed at the last minute). However, as with most of the formal EtE events, the planners clearly had made an attempt to include speakers representing diverse communities (e.g. young people, trans women, trans men, cisgender women, drug users, and Latin@), and these speakers weren’t able to take the stage until well after the appointed end time. So, these “community” members spoke to a much smaller audience than was present while the government officials were on stage.

One striking moment occurred in the middle of the event while the Gay Men’s Chorus performed in front of a screen broadcasting names of New Yorkers who have died due to AIDS-related complications. This performance was followed by local government officials (e.g. New York City council member Corey Johnson and New York State assembly member Richard Gottfried, both of Manhattan) reading aloud the names of their own constituents who had died. During both the performance and the reading of names, a noisy group of young people (possibly high schoolers from the neighborhood, but it was hard to tell) took up several rows of seats in the second balcony not far from where I was seated. The group laughed and yelled to each other

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16 The End AIDS NY 2020 coalition has proven an inimitable force in the course of the campaign. It seems to have grown out of the Kitchen Cabinet originally convened by Charles King, Mark Harrington, and other key activists behind Ending the Epidemic’s creation. Following the final Task Force meeting, the coalition continued to grow and became particularly vocal in advocating for the adoption of the Blueprint in Albany. It continues to organize events such as World AIDS Day 2015 and to coordinate and disseminate information related to ETE among members.
during this somber ceremony, which I found both disruptive and disrespectful. Yet no one, myself included, told them to quiet down or seemed to engage with them in any way.

I couldn’t help but be reminded of several interactions I have had with providers and activists who have been in the field for a long time. Hearkening back to the early days of the epidemic, these people have pointed out that “AIDS” used to be a household word and something that young people feared. For those young people who are now growing up in an age where HIV treatment is widely available and there is less fear around the virus, HIV prevention seems less relevant. As one pastor who leads churches in both Manhattan and northern New Jersey told me, “On this past Sunday, I just buried a young man that’s 30 years old. He died of AIDS. I visited him in the hospital. He was about 60 pounds and he had on a Pamper [diaper]. No reason for people to die of AIDS anymore. I haven’t seen anyone die like that in about 15 years.” Yet, some of these same providers and activists have told me that certain young people are very aware of HIV/AIDS and the government benefits extended to PLHA. Speaking of some of the young people she works with, Pastor Deborah told me:

…they have “positive parties.” I’ll call them “gift parties” …We call them “gift parties” because you go to get the gift, and the gift was HIV…In NYC, if I become positive and my viral load numbers are a certain amount, I can apply for HASA housing…Why should I go get HIV to have a place to stay?

According to Pastor Deborah, this desperation for housing among young people starts with being gay, being thrown out of the house, ending up on the street, and having “sustenance sex” for survival. Since I had heard others in the field raise the idea that young people are getting HIV on purpose, I asked Pastor Deborah if she was sure this was happening and she responded, “No question.” I have heard providers mention this phenomenon as well, including a provider, Cassie, who works specifically with transgender populations in the Bronx. In an interview with Cassie, she told me:
A lot of folks want to get HIV to get housing. To get housing because of HASA [New York City’s Health/AIDS Service Administration], although HASA can be very complicated and no good…especially the youth, they actually, or the older people that are over 50, they are having HIV just to get proper housing. Just to live properly out of poverty…

To be sure, the “poz parties” sound a bit like an urban legend and I have no firsthand proof that this is happening, but whether or not the phenomenon is real it is telling that the legend has spread. Clearly there is a perception among those in the HIV/AIDS field that young people, particularly young people of color who identify as MSM or as transgender (the populations with which Cassie and Pastor Deborah work the most), are so marginalized and desperate that they see HIV as a means to achieve a better life.

**Boots on the Ground: Reaching into Communities**

AIDS activists often like to talk about getting “boots on the ground,” indicating that the real work of HIV prevention, treatment, and care is leaving offices and health centers to talk with people in their own neighborhoods. I was able to attend one such event, an “End the AIDS Epidemic Town Hall Meeting” organized by the National Black Leadership Coalition on AIDS (NBLCA) in partnership with the National Action Network in Harlem. The purpose of the event was to educate Harlem residents who might not otherwise be effectively reached with EtE messaging and it seemed to accomplish this goal. Upon entering the meeting, I quickly realized that I was one of only a handful (about five or fewer in a group of about 50 people) of white people in the room and that I recognized very few faces from the AIDS service provider and activist communities. Overall, the mood in the room was warm, friendly, and slightly chaotic with attendees noisily greeting each other while small children ran underfoot (perhaps the only EtE event I attended where children were present).
Similar to events such as the “End AIDS 2020” July 2015 implementation summit and World AIDS Day 2015, this event featured speakers from city government and the NYC DOHMH, as well as Charles King and Damian, another Task Force member and sub-committee co-chair. In their turn, each panelist spoke briefly about Ending the Epidemic and then took questions from the audience. In contrast to other EtE-related events where participants seemed relatively educated about HIV transmission, treatment, and prevention, this group presented a different picture. At one point, a woman toward the front of the room stood up and proudly told the group that she works at a school in the neighborhood where “we’re trying to push abstinence.” This announcement did not draw a strong reaction from the room, though one of the panelists gently addressed it by speaking about how important it is to “meet them where they are” when working with young people, implying that young people are having sex and it is therefore best to discuss this with them. She went on to point out that HIV is no longer just a problem of the gay white men who started organizations like GMHC, but “it’s now in our yard” and legitimately affects the people of Harlem.

As Damian noted, this “yard” is not a hospitable place for certain people, especially those living with or at highest risk for HIV. Damian identifies as a young MSM of color and said that while growing up he was “taught that who I am is wrong.” Yet, “I could walk down the street and get hit on by men you wouldn’t even know,” suggesting that many of the men who hit on him walking down the street in Harlem appear to be heterosexual. Damian went on to recount the story of a young transgender woman who was recently beaten to death just around the corner from the NAN House of Justice (the meeting venue), telling the crowd, “we have work to do.” This young activist and public health professional, himself a resident of Harlem who is
considered part of a “key population,” therefore suggests that the neighborhood has a long way to go in terms of creating an atmosphere that effectively promotes HIV prevention.

However, this wasn’t the only picture of “community” that came up during the town hall. At one point, Charles King (who lives in Harlem) said to the crowd, “This is my neighborhood. This is my community.” A striking moment occurred toward the end of the meeting when the chair of the National Action Network’s HIV/AIDS Committee then thanked Charles for his work, calling him “Reverend King.” Indeed, Charles King used to be a Baptist minister and spoke to the town hall attendees as though they were his congregation (a strategy I have seen him employ before when speaking in Harlem). Yet, the symbolism was so striking, especially in a meeting room decorated with photos of the Reverend Martin Luther King, Jr., that I turned to an activist friend sitting next to me and we simultaneously raised our eyebrows.

Although we didn’t exchange any words, I can’t help but think that Fred and I had similar perspectives on this moment. First, that any comparison to Martin Luther King, Jr. is a bold one, and especially so when the person in question is white. In this respect, I also find Charles King’s identification of Harlem as “my community” somewhat unsettling. Historically, Harlem is predominantly African-American and the neighborhood itself is in some respects just as much as symbol as it is a physical place (Ellison 1964). Indeed, although I didn’t feel uncomfortable upon entering the town hall, I certainly felt out of place as a white woman. By claiming Harlem as “my” community, Charles is certainly correct insofar as he lives in Harlem and has long worked for social justice in the neighborhood. Yet, when it comes to persistent racial divides in New York City and to the identification of Harlem as a historically black community, there are certain lines that Charles may never cross due to his race. However, when the meeting organizer referred
to Charles as “Reverend King” he seemed to suggest a certain acceptance, as though Charles, a white man, could in fact be part of this majority-Black community.

**Discussion & Conclusions**

In conclusion, as Creed (2006) notes, the concept of community has the potential both to unite and to exclude. Participants in Ending the Epidemic often refer to themselves as part of various communities and in some ways to EtE itself as a community. At the same time, participants also refer to “community” as something that exists outside of the campaign in their neighborhoods or among their social networks. The issue of who is in and who is out of the EtE community became especially relevant at various events sponsored by activists in New York City. These events demonstrated which communities continue to feel marginalized in Ending the Epidemic, although some of these communities (e.g. the trans population) are increasingly gaining a voice in the EtE process through a formal advisory group and more inclusion at meetings and events. Others, like young people, are still an important community that hasn’t been adequately included in EtE implementation thus far.

Further, when it comes to the work of reaching out to community, a clear gender bias remains in AIDS activism and service provision. Many of the campaign’s most prominent figures are white men who have been in the field for decades. And although some of these figures now work in government, as one prominent AIDS activist noted at the July 2015 ETE implementation event in New York City, “I consider [Demetre Daskalakis] and [Dan O’Connell] activists.” Another prominent activist introduced Dan O’Connell to the stage during the same meeting and said, “Just because you work for the state, doesn’t mean you’re not an activist.” Campaign participants also seem to recognize the amount of power these men have, as exemplified during an informational webinar on EtE hosted by the New York State Psychiatric
Institute’s HIV Center. One participant repeatedly raised a question around the Task Force’s focus on affordable housing as a priority issue for the campaign. Since Charles King also is CEO of Housing Works, this participant suggested that a focus on housing ultimately is “self-serving” for Mr. King. This exchange is telling for the paranoia the participant clearly felt around the possibility that Charles King was exerting too much power. Indeed, seasoned and prominent activists in the campaign have risen to these positions through decades of building relationships and drawing on the political and scientific knowledge that served them in the early days of AIDS organizing (Epstein 1995). In addition to the social privileges they enjoy as white men, this knowledge positions them as powerful insiders in the field.

In contrast, it is the (white) women running the AIDS Institute’s Office of Planning and Community Affairs who have planned and executed all of the regional implementation meetings across the state in addition to administering to the implementation strategy survey. So, if Dan O’Connell and Demetre Daskalakis are considered part of the community of high-level AIDS activists, women like Diane of the Office of Planning and Community Affairs are the ones who are more involved “in” communities on the ground. These roles certainly align with scholarly work on perceptions of women as more grounded or “natural” than men ( Ortner 1972) and with works on women’s roles in social movements that point to women as “invisible” leaders ( McNair Barnett 1993). They also ring true with findings ( Irons 1998) that white women involved in the U.S. civil rights movement tended to engage in “low-risk institutional” activism in contrast to the “high-risk” activism of black women. According to Irons, this type of “low-risk” activism meant that white women were more likely to work in the safer environment of an organization while black women were more likely to engage in street activism that could put their lives in danger. However, McAdam (1992) would point out that in some ways white women were forced to work
in these “safer” environments due to expectations around traditional gender roles that aren’t extended to women of color in the same way.

In fact, many of the attendees at EtE regional implementation meetings I observed were women, and particularly women of color. Many of these women were health service providers. Although this type of work isn’t the kind of “high-risk” activism that Irons (1998) or McAdam (1992) describes, it does align with gendered and racialized trends in care-giving in the U.S. that have long skewed toward women of color disproportionately represented in the fields of healthcare and childcare (Jones 2009; Ginsburg and Rapp 1995; Brodkin Sacks 1987). Although these women literally work on the ground and “in” the community, they don’t enjoy the same kind of power and privilege that leading (often male) figures enjoy. So, the Ending the Epidemic community continues to be somewhat divided along lines of gender, race, class, and age, which may be one of the reasons why reaching the “hard to reach,” as exemplified in the anecdote opening this chapter, is so challenging.

Yet, “community” in the sense that Williams refers to it as a “sense of direct common concern” and “the materialization of various forms of common organization” is still a very relevant concept for AIDS activism and one that government-led initiatives seem eager to call upon in the interest of furthering a population-level agenda. In this way, “collaboration” has become an important concept that is used to mobilize providers around a “sense of common concern” while downplaying the competition providers face amongst themselves for limited funding. In several cases, the mandate to collaborate is offered alongside calls for providers to take responsibility for themselves; a call that also can be extended to patients, who may not have the resources to do so.
Following a longstanding tradition in AIDS activism, collaboration and community still seem to be salient concepts for providers and activists alike, and ones that have motivated successful initiatives like McPETE. However, while providers seem eager to participate in collaborative efforts (if sometimes because participation is required), they also express concern that they are being asked to do too much when they are already resource-constrained, and question whether or not participation in several collaborative efforts is truly necessary.

Community engagement is absolutely integral to work in the HIV/AIDS field and in some respects this focus is one of the great achievements of the movement as a whole. However, when healthcare reform in New York State increasingly leans on providers to work beyond their job description and initiatives like EtE suggest that everyone in the community is responsible for the campaign’s outcomes, much of the responsibility for work on the ground ultimately falls on those with historically little power, further raising questions of how power is distributed in the campaign. In this case, a group of seasoned white male activists and government officials call on meeting rooms full of people (mostly women) of color to do this work, thereby upholding dynamics that both put them in power and uphold a system that prizes individual responsibility. Although it is not an intentional effort to demarcate black versus white, male versus female, it still has this effect. Further, this system may be what positions many health service providers as “non-traditional partners” (a comment raised to much laughter at the Staten Island EtE regional implementation meeting) in a campaign like Ending the Epidemic. For those who are under so much pressure just to serve patients, their ability to engage in multiple communities is limited and the communities they work with on a daily basis must take precedence over larger collective efforts like the Ending the Epidemic campaign.
CHAPTER 3 The Power of Data

“[This] information is numeric; it’s not informational.”
- Task Force member discussing the available data on HIV medication adherence at the November 18, 2014 Task Force meeting

“There are big lies, small lies, and statistics.”
- Task Force member at the December 15, 2014 Task Force meeting Prevention breakout session

In the midst of discussing a recent training on quality improvement and data for “consumers” at an NY Connects Western New York regional meeting, Juan proudly held the flashdrive strung around his neck in the air. Cynthia raised hers too, in apparent solidarity. Even before learning what the flashdrives contained, I was struck by this moment, which was reminiscent of fists raised in the air in both power and protest. The flashdrives had been distributed at the quality improvement training and contained all of the meeting materials, and I had noticed a number of people wearing them as I arrived late to the meeting that morning. As discussion went on, those in the room who had attended the training clapped enthusiastically for the AIDS Institute staff member who had led the training and thanked him for his work, indicating their deep appreciation.

It was only as I continued to work with NY Connects and to delve more deeply into Ending the Epidemic that I really came to appreciate both this moment in upstate New York and the overall significance of the quality training aimed at HIV-positive “consumers.” As Juan and Cynthia were indicating at the NY Connects meeting, knowledge is power. And this trope has been particularly relevant to AIDS activism since the early days of treatment advocacy. In contrast to those early activists who were mostly white men, though, Juan is Latino and Cynthia was among several women in the room who also had attended the training. The flashdrives raised in the air appeared to be an acknowledgement that these people finally held the power of
knowledge in their hands. Yet, their effusive praise of the AIDS Institute for hosting the training also indicates that these windows into the world of knowledge management and data continue to be few and far between for the New Yorkers most affected by HIV/AIDS. Indeed, the AIDS Institute staff member who organized the training congratulated attendees and referred to them as “pioneers” for participating in the first training of this kind in New York State.

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This chapter focuses on the politics of knowledge in Ending the Epidemic, analyzing how data, documentation, and knowledge management reflect power relations within the HIV/AIDS field in New York. Epstein (1996) has shown how, in the early days of the AIDS epidemic, the generation of credible scientific knowledge was relatively democratic, and allowed for contributions from AIDS activists and the public in a way that is unusual for scientific research. Still, gendered and racialized inequalities persisted, and women and people of color struggled for representation in clinical trials (Susser 2009). Knowledge generation and management, particularly who has the authority to participate in generating and disseminating credible scientific knowledge, has therefore been a major touchstone in the field for much of its history.

In the case of Ending the Epidemic, data collection and tracking is a major component of the campaign. According to the campaign’s official messaging, EtE is defined by New York State’s ability to lower the number of new HIV infections to below 750 per year, which is the rate at which the epidemic will start to die out. Although many acknowledge that the campaign’s goals are actually much loftier, recognizing the official “end” of the AIDS epidemic in New York State therefore hinges on the state’s ability to accurately track and document data around new infections. Much of the data on which the campaign depends is gathered and reported to the state by AIDS service providers who are over-worked and under-funded. These providers often
express confusion and frustration with the amount of time and effort it takes to use state databases, creating further stress in their jobs. When EtE leadership and prominent activists (mostly white men) make decisions about what information counts as meaningful, these decisions affect the daily work of those (mostly women, and particularly women of color) working in healthcare on the ground. So, while the campaign appears to welcome and seriously consider data-related input from AIDS activists and service providers, the question remains as to how much involving the “public” in these decisions and making data “transparent” really makes knowledge generation and management more open and democratic.

**Literature Review: Scientific Knowledge & Authority**

As Epstein (1996, 1995) has pointed out, because one person alone cannot know all there is to know about a particular subject, the creation and dissemination of scientific knowledge depends heavily on networks of trust and credibility. However, these networks often are within the “boundaries” of a scientific community, which separate scientific authorities from others (Gieryn 1983). Citing Darnton (1984), Lamont and Molnár (2002: 179) note that drawing any kind of boundary ultimately is an exercise in power. Thongchai (1997) and Verdery (2003) draw similar conclusions regarding geographic boundaries and map-making, which have implications for statecraft. Indeed, the very act of “documentation” and what is translated onto paper is itself laden with power relations and political consequences (e.g. Hull 2012; Gálvez 2011; Currah and Moore 2009).

Foucault (1978) has suggested that collecting and documenting population-level data is one of the ways in which modern states enact power. Much of this data is gathered in numeric form, which appears to be straightforward, transparent, and neutral. However, according to Poovey (1998) numbers are instead laden with assumptions about what kind of phenomena
matters enough to be counted and consequently how the world should be understood. Merry (2011) suggests that indicators functions as a form of governance when they are used to measure global NGO work. While quantitative indicators appear to be neutral and value-free, they actually are a technology of power. She writes:

In some ways, indicators are like witchcraft…[they] are a technology that exercises power but in a variety of ways, depending on who is using it for what purposes. And like witchcraft, indicators presume a system of knowledge and a theory of how things happen that are hegemonic and rarely subjected to scrutiny, despite their critical role in the allocation of power. (Ibid.: S92)

In short, Merry suggests that indicators both contain and hide power relations, and as such they can be used in the service of power. Similarly, Scott (1999) contends that measurability allows for standardization, which has been a tool of modern state-making. Although Ferguson (2005) maintains that this principle does not hold true under global capitalism.

In order to cross the boundary into a scientific or knowledge community, it is necessary to establish credibility. According to Latour (1988), the most effective claims to knowledge credibility come from creating “obligatory passage points,” such as a journal article that must always be cited. Epstein (1996) suggests that AIDS activism has created a class of “lay experts” whose knowledge is fully credible within the scientific community. On the one hand, these activists have “imbibed and appropriated the languages and cultures of the biomedical sciences” (Ibid.: 335) to the extent that they have become an “obligatory passage point” in the design of clinical trials and scientific protocols (Ibid.: 336). On the other hand, they also bring what Haraway (1990) refers to as “situated knowledges,” which are based on personal experience and convey a type of expertise that many researchers (who are not themselves directly affected by HIV) do not have. Yet, Epstein acknowledges that even with the creation of the lay expert, the generation and mediation of knowledge around HIV/AIDS remains unequal. He writes:
knowledge hierarchies are rarely ‘accidental’ in their origins: They tend both to build upon and reinforce social cleavages based on other markers of difference—class, formal education, race, gender, sexuality, and nationality. When the power of expert knowledge within a social movement overlaps with other systems of hierarchy, the results can be problematic for the movement, even if the new experts work entirely in good faith for the benefit of all…These considerations suggest the true dimensions of the problem: it is unlikely that knowledge-making practices can be substantially democratized, except when efforts to do so are carried out in conjunction with other social struggles that challenge other, entrenched systems of domination. (1996: 352).

Here, Epstein points out the overlap between power hierarchies and knowledge creation, and suggests that social movements are hindered by processes of knowledge creation that have not been sufficiently “democratized.”

Feminist anthropologists have explored this theme of overlap between power and scientific knowledge extensively. As Franklin (1995) notes, “Feminist anthropology was a critical testing ground for biologisms from the mid-1970s onward, and it is no coincidence that many leading feminist scholars are now engaged in the anthropology of science” (170). Much of this more recent work has focused on new reproductive technologies, which is no surprise given that it was precipitated by feminist studies of gender and kinship. Feminist scholarship in this area suggested that supposedly objective biological “facts” are instead subjective and socially framed, calling into question assumptions in the anthropological literature about the relationship between biology and kinship (see Strathern 1992a, 1992b; Collier and Yanagisako 1990). Families are formed in many ways through, for example, adoption (Gailey 2010), in vitro fertilization (Inhorn 2006), and surrogacy (Deomampo 2015; Vora 2009). Yet, the ways in which kinship is understood always stems from historical and locally situated understandings of family.

Similarly, understandings of what constitute sex and gender also are historically and culturally determined. Feminist philosophers like Judith Butler (1990) claim that gender itself is a social construction that comes to be “naturalized” through the body, and other social scientists
suggest that assumptions about sex itself as a biological designation and the physical characteristics that are meant to accompany this designation may be incomplete and even inhibit real scientific progress (Jordan-Young 2011; Fausto-Sterling 2005). Indeed, feminist anthropologists also have pointed to the ways in which the supposedly objective languages of science and medicine contain stereotypical assumptions about gender (Martin 1991) and class (Rapp 2000).

What these disparate works have in common is an underlying (or sometimes explicit) assertion that scientific knowledge is crafted within larger power relations that are patriarchal and that are circumscribed by race and class. Thus, authoritative scientific knowledge often carries these power relations within it; data and numbers are gendered and raced. In a sort of feedback loop, this means that women and people of color tend to be underrepresented in positions where powerful scientific knowledge is created (Nelson and Brammer 2010; Tullo 2007). This is often because they are perceived as less capable of doing the work and consequently they are less likely to be hired and/or promoted (Kay and Gorman 2012; Kelly and Grant 2012; Benard and Correll 2010; Braddock and McPartland 1987). When women and people of color are underrepresented in these positions the gendered assumptions and language that Martin (1991) points to become more prevalent. This both encourages the employment cycle to continue and also leads to women and minorities being either under- or over-represented in, for example, pharmaceutical trials (Curno et al. 2016; Abadie 2010). In the case of measurement indicators, the gendered and raced nature of numbers becomes all the more important. If, as Merry (2011), Scott (1999) and others suggest numbers and measures are a tool of governmental power, missing or misrepresenting particular social groups in these numbers has important consequences for government programs and policies. This is particularly relevant to Ending the
Epidemic, which depends on “hard” data both to justify programmatic priorities and to determine its own success or failure.

End of the Epidemic Must Be Measurable

While Ending the Epidemic participants interpret the campaign’s goals somewhat broadly (see Chapter 1), most agree that EtE’s purpose from an official standpoint is to reduce the number of new HIV infections in New York State to below 750 per year. Thus, as one speaker at the July 2015 “Ending AIDS 2020: Blueprint to Action” event noted, “Ending the epidemic is a numbers game.” Indeed, official EtE events always feature at least a short presentation on the statistics behind the epidemic, such as HIV prevalence and incidence for the state as a whole and broken down according to sub-population and by neighborhood or region. These presentations became so standard that a panelist at the “Blueprint to Action” event jokingly announced “This is the numbers panel!” when a group of epidemiologists took the stage. Indeed, citing statistics is a common and relatively easy way to lend legitimacy to an effort like Ending the Epidemic.

Yet, the campaign also must prove its legitimacy as it unfolds. The only way to know if Ending the Epidemic is achieving any of its goals is by tracking the numbers according to agreed-upon measurements and indicators. So, from the beginning EtE has relied on the expertise of epidemiologists, data scientists, and activists known for their work in the realm of scientific data to build the campaign and its internal monitoring mechanisms. Even before the Task Force officially convened, the AIDS Institute, the HIV Center for Clinical and Behavioral Studies at Columbia University and the Treatment Action Group (TAG) convened a full day meeting titled “Defining the End of the AIDS Epidemic in New York State - Models and Measures: Priority Metrics for Ending the Epidemic.” Although this meeting was scheduled well in advance, it ultimately fell the day after the very first Task Force meeting (for which some
attendees received only 24 hours’ notice). While the first Task Force meeting was held outside of Albany and the metrics meeting was held at Columbia University, a number of Task Force members also attended the metrics meeting, signaling its importance in the scheme of the campaign. Indeed, close to 30 people (about half the size of the full Task Force) were squeezed into a small meeting room at Columbia, prompting one of the organizers to joke that they were trying to win a contest for “most epidemiologists in a phone booth.”

Further indicating the importance of data and indicators to the EtE process, the Task Force itself included a “data” sub-committee to develop internal measurements and indicators. This sub-committee was comprised largely of epidemiologists and data scientists or, as an activist member of the sub-committee jokingly stated, “The Data Committee was relatively small and pretty academic, with the exception of me.” And while the Blueprint recommendations were left intentionally “flexible” according to the organizers, one of the few concrete actions included in the document was the creation of a “dashboard” website to track state-wide progress toward achieving the campaign’s goals. This website has since gone live under the direction of the CUNY School of Public Health (more on this below).

Among all of these elements of Ending the Epidemic, the prevailing theme is a focus on numbers as the primary source of data and the indicators of success. However, many involved in the campaign would define EtE’s goals somewhat more ambiguously. For example, Demetre Daskalakis called for a “new epidemic of love, respect, and justice” at the October 2015 town hall hosted by the National Black Leadership Commission on AIDS in Harlem. Similarly, members of ACT UP regularly suggest that the campaign should really aim to connect every New Yorker to primary healthcare; a goal that AIDS activists have been championing for a long
time. Unlike the campaign’s official goals, these broader visions aren’t quantifiable or even measurable in the same way.

**What Is Measurable and What Counts as Evidence?**

So, when Ending the Epidemic organizers talk about “data,” most of the time what they really mean is “numbers.” And the ability to quantify social phenomena has implications for claims to campaign legitimacy, as well as for developing programmatic focus within the campaign and allocating resources to priority areas. Thus, often when Ending the Epidemic organizers give presentations related to the campaign, they refer to statistics regarding overall HIV prevalence and incidence in the state, as well as prevalence and incidence broken down by region and by population. These figures are included on the Ending the Epidemic Dashboard site, indicating that they are some of the key metrics by which campaign success will be measured.

As Merry (2011) defines them, indicators are:

… statistical measures that are used to consolidate complex data into a simple number or rank that is meaningful to policy makers and the public. They tend to ignore individual specificity and context in favor of superficial but standardized knowledge… The essence of an indicator is that it is simple and easy to understand. Embedded theories, decisions about measures, and interpretations of the data are replaced by the certainty and lack of ambiguity of a number (S86).

So, in essence indicators simplify the politics of a social phenomenon and distill them into a number. And once this distillation has taken place, the politics are hidden. Further, as the director of HIV Prevention at the NYC Department of Health and Mental Hygiene (DOHMH) wrote in a PowerPoint presentation on PrEP measurement: “If you can’t measure it…you can’t manage it” (Myers 2016). So, once a phenomenon becomes measurable, it then becomes manageable by the state.

Ironically, though, the numbers used to measure campaign success often are inaccurate or incomplete. For example, at the October 2014 metrics meeting, the group discussed New York
State’s HIV care cascade. The cascade is a commonly used tool that indicates quality of care. Beginning with an estimate of the total number of persons living with HIV in a given population (HIV prevalence), in successive steps the cascade shows the percentage of these persons who have been linked to care, the percentage retained in care, and the percentage who are virally suppressed; indicating that they are adhering to their treatment regimen and have their HIV under control (Gardner and Young 2014; Mugavero et al. 2013). However, as a representative from the Department of Health noted at this meeting, “As you look at our cascade, we know that those are not real numbers. They’re numbers based on assumptions.” In fact, another meeting attendee said that estimating HIV prevalence is “the Achilles heel of our surveillance [data],” since the only way to truly calculate prevalence is to conduct a serosurvey. Serosurveys involve collecting blood samples from a population rather than relying on reported data to calculate HIV prevalence. However, they can be difficult to do and may not be accurate in populations where a large percentage of people already know their HIV status (Floyd et al. 2013).

So, because each successive step of the cascade depends on the previous step, an inaccurate estimate of HIV prevalence affects the entire cascade. Further, the way in which each step of the cascade is defined also affects the overall picture of quality of care. During the October 2014 metrics meeting, for example, one participant raised the question of how the Department of Health defines “viral suppression.” A DOH representative responded that they use the indicator recommended by the U.S. Department of Health and Human Services (200 copies of the HIV virus per 1 mL of blood,\(^\text{17}\) but this indicator can vary across time and raises questions of “durable” viral suppression.\(^\text{18}\) Thus, a slightly different definition of viral suppression and sampling at a different point in time could generate different results. As another meeting attendee from the Department of Health pointed out, “As you look at our cascade, we know that those are not real numbers. They’re numbers based on assumptions.” In fact, another meeting attendee said that estimating HIV prevalence is “the Achilles heel of our surveillance [data],” since the only way to truly calculate prevalence is to conduct a serosurvey. Serosurveys involve collecting blood samples from a population rather than relying on reported data to calculate HIV prevalence. However, they can be difficult to do and may not be accurate in populations where a large percentage of people already know their HIV status (Floyd et al. 2013).

\(^{17}\) As found on the Department’s website: [https://www.aids.gov/pdf/hhs-common-hiv-indicators.pdf](https://www.aids.gov/pdf/hhs-common-hiv-indicators.pdf)

\(^{18}\) Whether or not viral load suppression endures over a period of time (Benator et al. 2015).
participant pointed out, then, “Hopefully, there is consistent inconsistency” in the numbers that the Department of Health ultimately generates.

Further, there are cases in which measurement appears straightforward, but the indicator being used doesn’t adequately reflect the phenomenon it is meant to capture. For example, condom distribution has long been used as an indicator of effectiveness and reach among HIV prevention programs. At a presentation to the AIDS Advisory Council’s Ending the Epidemic sub-committee, for example, Demetre Daskalakis illustrated the effectiveness of New York City’s condom distribution program with numbers of male (37.2 million) and female (1.2 million) condoms distributed in 2014 (Daskalakis 2015). However, condoms distributed does not necessarily translate to condoms used and especially to condoms used correctly. Personally, I recently threw away a large number of expired NYC brand condoms I had acquired over the years at various public health events. The condoms often are included in gift bags with other goodies and informational pamphlets and so I did not pick them up by choice, but rather received them as “gifts.” Further, when I interviewed Christina, a youth health educator, she pointed out the barriers to effective condom use among young people. Although New York City may make condoms widely available for free, “There’s this misconception about NYC Condoms and how they break.” Part of the problem, Christina says, is that many young people don’t know how to use a condom correctly in the first place, and so they are more likely to break: “You’re saying, ‘oh, this is HIV prevention,’ but then you don’t even know how to use it.” Christina also reported that she was having trouble distributing certain types of condoms over others. Trojan’s extra-large “Magnum” condoms (New York City now makes a similar “Kyng” condom in a gold wrapper) are in high demand: “I would have to be like ‘there’s Magnums in there’ for them to take it.” However, Christina suspects this is “just an ego booster,” suggesting that young men
want to prove their masculinity by taking extra-large condoms that won’t necessarily fit them. Thus, citing the number of condoms distributed by New York City in a presentation on the City’s HIV prevention efforts may not be an accurate measure of prevention. But “If you can’t measure it…you can’t manage it,” then in some respects accurate measurement may be less important than the state’s very ability to measure and therefore manage a particular phenomenon.

Where Does Data Come From?

Generally, when Ending the Epidemic participants and organizers discuss data and its sources, they refer to data that is generated by providers and labs and reported to the state or to New York City. This reporting occurs through various mechanisms, such as the state surveillance system. In 2000, New York State Public Health Law Article 21 Chapter 163 mandated that health service providers, medical laboratories, and tissue banks had to report all new diagnoses of HIV, AIDS, and HIV-related illness and known sex or needle-sharing partners to the state. AIDS Institute staff report that the surveillance system will soon start collecting information on PrEP as well. Further, service providers who receive funding from the AIDS Institute are required to submit reports to the state through the AIDS Institute Reporting System (AIRS) and eHIVQUAL, the state’s system for reporting on HIV quality measures.

NY Connects also has proven to be a relatively useful mechanism for collecting data on quality of care to feed into the EtE process. While the initiative technically focuses on improving linkage, retention, and viral load suppression, it requires participating sites to report on these measures through a centralized system. One of the NY Connects planners has suggested that the data generation and collection component is just as important as the programmatic aspect of the initiative, and indeed NY Connects has become one of the major data sources for the Ending the Epidemic dashboard site.
Another data source that is particularly relevant to EtE and that organizers discuss often is the Medicaid database. Since Medicaid is the largest source of healthcare coverage for PLHA (Kates 2011), Medicaid providers in particular tend to capture a lot of HIV-related information. During the October 2014 metrics meeting, participants discussed Medicaid as a major source of data and a humorous exchange broke out as follows:

Participant 1: “I assume we could steal their metrics.”

Participant 2: “Steal their metrics or use their data?”

Participant 3: “Steal their data”

The other participants responded to this exchange with laughter, but it certainly illustrated the group’s prevailing attitude toward the centrality of Medicaid data in the EtE process.

Further illustrating the importance of Medicaid data to Ending the Epidemic, the idea of tapping into the Medicaid database to gather information on PrEP users became a particularly contentious topic of conversation during both the October 2014 metrics meeting and some of the Task Force meetings. Since currently there is no centralized data source on PrEP use in New York and improving access to and uptake of PrEP is one of EtE’s three main pillars, the ability to measure and track PrEP uptake and adherence has been a major concern for the campaign. During a session titled “Community Perspectives on Metrics” at the October 2014 metrics meeting, a member of ACT UP (Tim) presented a model for creating a registry of PrEP patients using data available through Medicaid. This proposed model involved using the Medicaid database to track the number of prescriptions filled with a PrEP indication, as well as prescription refills as a proxy measure of medication adherence. The presentation was technically sophisticated, even over my head at times, and involved several PowerPoint slides with detailed graphs of how the registry might work. At one point, Tim suggested it would be
possible to use “graph theory” to develop a population-level view of how the epidemic is structured in New York. An attendee from CDC then jumped in to point out that another scholar had already used this method and a moment of tension ensued as the two argued back and forth about whether or not the method was worth pursuing. This moment was clearly a contest for power between the seasoned CDC expert and the much younger AIDS activist with scientific knowledge as its medium.

After some debate regarding the creation of a “PrEP registry” at the metrics meeting, this idea was taken to the full Task Force, where it was ultimately denied. At the metrics meeting, the CDC representative noted that the idea of creating a database of people with highly stigmatized behavior “Makes me nervous.” Similarly, many on the Task Force shared the sentiment that creating a database of socially disadvantaged persons with a history of stigmatizing behavior was unethical. As one Task Force member said at the November 18th meeting, “The word ‘registry’ I think sends chills down the spines of many of us.”

The discussions of Medicaid data and particularly those around using the data to create a “PrEP registry” are revealing for several reasons. First, they demonstrate an awareness among EtE participants of what lies “behind” the numbers. Task Force members expressed apprehension and ultimately blocked the PrEP registry from moving forward due to their concern that the patients captured in the Medicaid data already are vulnerable to exploitation and possibly even to criminal charges. In this case, data had a human face and very human consequences.

The PrEP registry presentation at the metrics meeting also is noteworthy for the way it illustrates higher-level power dynamics around data in the campaign. The presentation was conducted by Tim, a young white gay man who plays a prominent role in ACT UP and who also is pursuing a degree in the natural sciences. Echoing earlier days of AIDS treatment activism
(e.g. Epstein 1996), Tim asserted his legitimacy in a meeting of researchers and high-level public health officials through the language of science, even engaging in an academic debate with a representative from the CDC. Also similar to the AIDS activism of the 1990s, Tim is white, gay, and educated. In fact, I noted that almost everyone in the meeting was white, except for one Asian man and one black women, both of whom appeared to be AIDS Institute employees and who sat in the back without contributing to discussion. The majority of those seated around the main meeting table were men. This seems to provide a high-level view of who curates and manages the data used in and for official campaigns like Ending the Epidemic.

On the other hand, discussions with NY Connects participants who are in charge of submitting data reveal that this work often is time-consuming for providers on the ground, particularly when systems are confusing to navigate or regularly suffer technical failures. While some sites that are well-resourced are able to hire data teams, others have complained that data submission is yet another thing to do on a long list for providers who already are pulled in multiple directions. In contrast to those seated at the table during the metrics meeting, NY Connects is comprised of more women and people of color. This echoes a larger trend in care work, and particularly in healthcare, in which women of color have long been over-represented at the lower levels of employment (Jones 2009; Colen 1995; Wiggins 1995; Brodkin Sacks 1987). Similarly, I was struck by a moment during an interview with a prominent activist, a transgender woman of color, when she told me about walking the streets of the Bronx in the middle of night to collect data on trans sex workers:

Actually tonight, I’m supposed to beat the streets from 12:00 until 3:00 in the morning...to find the trans women and men that’s out there and talk to them and give them some healthy kit packages like healthy crack pipes, new syringes... I have two other female [sic] that...they are going to volunteer with me for 90 days. And after 90 days and we are able to collect any kind of data...I’m gonna write a report and see if we can get some sort of funding...
As these examples illustrate, there seems to be a gap between who collects data and who manages it at the top. Indeed, much of the data that EtE relies on comes from the state, but it is gathered by health workers, largely women of color, on the ground. This disparity was particularly brought to light in the PrEP registry debate. Here, two white men in relatively privileged positions debated whether or not to create a controversial registry of people who already are stigmatized and marginalized in the name of gathering data. Although this idea was struck down by the Task Force, it demonstrates both the power of knowledge creation and management as a motivating force, and its ability to paper over the epidemic’s underlying politics.

**Data Access: The Problem of “Siloes,” “Gaps,” and “Velocity”**

Who has access to data once it is generated also has implications for Ending the Epidemic’s success. No matter how much data is technically available, activists and providers need access to this data in order to translate it into action, and this access often is hindered by “gaps” in data, “siloes” among data sources, and the “velocity” at which data can be turned around to the public. In cases where data either isn’t available or it is inaccessible due to restrictions or “siloes” in data sources, “gaps” in knowledge can occur. As one participant noted during the November 18th Task Force data committee meeting, community-based organizations (CBOs; i.e. organizations that do not provide direct HIV treatment services) often don’t have access to data on patient medication adherence. Instead, these organizations must rely on patient reporting, which is not always reliable. This gap in knowledge makes it more challenging for CBOs to provide quality services for patients. Another type of knowledge gap occurs at a higher level when data is managed by entities other than the state. During the October 2014 metrics meeting, for example, a participant from the AIDS Institute raised a question around how to
measure quality of care using viral load suppression as a proxy. Another participant replied, “The data are there, we just can’t get our hands on it.” The participant noted that this data is held by pharmaceutical companies and as a result the Department of Health does not have access to it. This scenario illustrates what EtE participants often refer to as data “siloes”: since different types of data are collected and held by different entities, it can be challenging to both access data sources across these “siloes” and to bring them together in a meaningful way.

In an effort to close some of these gaps and to make surveillance data more available and user-friendly for providers, New York’s Public Health Law has recently been updated to allow service providers to share some patient data with each other in order to better track patients who may have fallen out of care (New York State Department of Health AIDS Institute 2014). Clearly this change has been meaningful for providers, since it came up as a point of discussion during an early AIDS Advisory Council EtE sub-committee meeting and two NY Connects sites in Western New York set up a formal system to share information about out-of-care patients shortly after the law was passed. Programs like NY Connects and NY Knows also act as venues for breaking down siloes and for sharing data amongst sites by disseminating site- and regional-level data to participating sites in an effort to encourage quality improvement efforts within and among participants.

An additional component of making data available and useful to the public is the speed at which data can be generated and then disseminated; what one member of the Task Force data sub-committee calls “data velocity.” Even (or maybe especially) epidemiologists at the AIDS Institute recognize that data often takes years for the state to generate as it cleans, processes, and approves the numbers that come in from providers. As the data sub-committee discussed at their November 18th meeting, from a public health perspective it would be ideal to instead gather and
publish data in real time so that there can be “redress” as issues come up among certain sub-populations. So, the Task Force recommendation to create a Dashboard site was partly to address this issue of “data velocity” by making data turnaround more “timely” and “interactive.”

**Data Transparency Is a Way to Address “Siloes” and “Gaps”**

Transparency was a key theme that came up repeatedly during the early Ending the Epidemic process, and this theme also relates directly to data access. This focus on transparency appears to have been a response to the history of AIDS activism, which has seen activists at odds with researchers and government authorities who would not (or perhaps could not) include activists in high-level decision making processes. This resulted in AIDS activists embracing the principle of “Nothing for us [or sometimes “about us”] without us,” which means that all decision making should meaningfully include the perspectives of PLHA (De Cock et al. 2011). From this perspective, transparency of state processes facing outward is a core component of Ending the Epidemic. Not only did the campaign organizers aim to include a range of participants in the Task Force process, including a number of participants openly living with HIV, but keeping meetings open to the public and posting materials to the AIDS Institute’s public website clearly was meant to share information with the public and therefore “include” a much larger population. Indeed, at one point during the October 2014 metrics meeting, a prominent AIDS activist appealed to government representatives in the room, asking them to share data with the public and in particular to point out the weaknesses in the data, saying “I hope you trust us enough, as we are now partners.” A second element of transparency that is less about being inclusive, but equally as important to the outcomes of EtE, is transparency within and among organizations. In particular, data transparency is one of the key ways in which Ending the Epidemic aims to improve quality and reach of care, and ultimately achieve its goals.
Transparency Type 1: State facing outward

Ending the Epidemic organizers often stressed that creating the Blueprint was meant to be a “transparent process” that was “fully documented” and even affiliated events feeding into the Task Force process, such as the October 2014 metrics meeting, had a policy of transparency. In this vein, all Task Force meetings were recorded and posted to the AIDS Institute website and all of the Blueprint recommendations received via the online Survey Monkey were posted as well. In addition, Task Force meetings were theoretically open to the public, as are the ongoing meetings of the AIDS Advisory Council EtE sub-committee. However, the AAC meetings are held at the AIDS Institute’s offices in downtown Manhattan and the Task Force met in these same offices several times as well. Due to its location, this building has heavy security and can be difficult to access for those who are not AIDS Institute staff or who have not been invited directly to a meeting.

Further, while the Task Force meetings were supposed to be open to the public the organizers regularly scheduled time into the agenda for individual sub-committees to meet separately. In these cases, the meetings were closed door and even I was only occasionally allowed in to observe despite my working relationship with the organizers. The process therefore became far less transparent as I was literally shut out from the sub-committee meetings. So, what was made transparent on the AIDS Institute website ultimately was a distilled version of the Task Force process. To be sure, making recordings or notes available from every sub-committee meeting may have been logistically impossible. All of the Task Force members I interviewed, and particularly the sub-committee co-chairs, reported holding regular calls and emailing often between face-to-face meetings as well. As one co-chair, Damian, said, “Me and my co-chair was always communicating. We were texting, we were emailing…People [inaudible] saying to us
that they thought we were best friends for years.” This is a somewhat extreme example and also points to a particularly good fit between the co-chairs, but it certainly was common for Task Force members to joke about the sheer amount of time they spent on EtE work between meetings. Still, one of the Task Force members suggested that the big decisions had been made ahead of time in anticipation of the short timeline the Task Force would have to turn around a Blueprint for the governor: “To a certain extent, there was sort of a pre-determined outcome…not explicitly…a collective sense that ‘yeah we’re gonna get this done and we’re gonna agree to these things.’ Not that there wasn’t healthy debate…”

So, even in a process that aimed for so much transparency, the amount of information that ultimately was shared with the public was still limited. And as the Task Force member pointed out above, the real decisions may have been made before the Task Force even started, perhaps rendering these attempts at transparency less effective. Or, as one member of the data sub-committee suggested, engagement may have been uneven among participants to begin with, ensuring that those who already held leadership positions would continue to have the most input. As he said, “when you get down to it, what really shapes it is what gets documented and written and shared…from that standpoint it was really just a handful of us that did the editing of these recommendations.”

The Ending the Epidemic Dashboard

One of the main reasons why transparency is so important is because it invites public interaction with a political process. Campaign organizers clearly attempted to engage the public in multiple ways during the Task Force process, but moving forward a main focus appears to be on transparency and interactivity around data. As the Blueprint states:

Stakeholders involved in implementing the New York State plan to end the epidemic will be able to access and use key data points and indicators. This will allow stakeholders to
successfully target, implement, and evaluate HIV-related prevention, care, treatment, and supportive services to achieve the three point plan [to end the epidemic]...The Ending the Epidemic Task Force process was transparent and promoted public access through all stages of the Task Force work. The implementation and monitoring phases will encompass a six year timeframe that will also reflect public input and support. (New York State Department of Health 2015: 32-33).

Indeed, while most Blueprint recommendations were left intentionally broad, one of the few recommendations calling for a specific action is Blueprint Recommendation (BP) 29: Expand and enhance the use of data to track and report progress. This recommendation states:

The creation of a web-based, public facing 'Ending the Epidemic Dashboard' is recommended to broadly disseminate information to stakeholders on the Initiative’s progress. This would include reflecting trends and county-level maps of key metrics related to the initiative, and should be updated quarterly (Ibid.: 28).

I first became aware of the Dashboard proposal at the October 2014 metrics meeting when one of the participants, an epidemiologist named Peter, spoke up and said, “I think we need a dashboard.” Peter suggested that this website could bring together “traditionally silo’d information” in a way that was “outward facing” and “interactive” with “feedback loops” and “actionable items.” As a member of the Task Force data sub-committee, Peter raised this same point again. When I interviewed him later about how the Dashboard was developed he said:

One of the recommendations of the data sub-committee that I developed was around this need for a dashboard system...Whatever the metrics are, the components of the initiative are to end the epidemic, there needs to be some place to track the progress and document the success or failure of this initiative...And so, I made a very specific recommendation about a web-based...dashboard...

The idea for a dashboard, he said, came from work he had done previously for the U.S. government:

I’ve done a dashboard system in the past as part of some of my international work whereby we would have a lot of data streaming from various countries and clinics and a lot of different people needed to access it and use it. And this model of receiving data and generating an annual report or answering people’s queries about the data in an ad hoc way just wasn’t gonna work. The demand and desire to be able to view and use the data was so high and de-centralized that I realized quickly that we needed to have a web-based
system that people could just log into and see the data and slice and dice it as they like. Even though the data were not perfect and a little bit messy…A lot of the principles that I am bringing to this dashboard project, like being able to see things at a very high level, the country level, the regional level. But also being able to drill down very far into an individual site or a sub-group of people within an individual site. This idea of integrating data across different realms that were previously silo’d.

In short, the Dashboard was meant to act as a centralized site to gather and display data. In this way it would begin to address the problem of “silo’d” sources that limited data accessibility.

The Dashboard site went “live” in September 2015. As shown below in Figure A, the site opens to a page that rotates announcements regarding updates to the site with information on the Ending the Epidemic campaign and visualizations of data, such as the HIV care cascades for New York State. Below, informational tiles display statistics related to Ending the Epidemic’s goals, such as HIV prevalence in New York State and the percentage of people recently tested in New York City. Moving through the site, users have the ability to view data at the level of their own neighborhood and to sort by demographic factors such as gender and age.

Figure 1. The New York State Ending the Epidemic Dashboard website

According to the site, data for the Dashboard comes from a range of sources managed by both the New York State Department of Health (DOH) and the New York City Department of Health and Mental Hygiene (DOHMH). These sources include surveillance data, vital statistics, NY Connects, and HIVQUAL from the DOH as well as New York City’s Community Health Survey (DOHMH).

The October 2014 metrics meeting was a first step toward determining which metrics could be used in the campaign and ostensibly the Task Force data sub-committee should have been a next step in this process. However, there was a conflict of timelines with the individual sub-committees meeting to decide what to measure while the data sub-committee simultaneously tried to determine how to measure it. As David, another member of the data sub-committee noted, most of the recommendations that came in through Survey Monkey focused on one of the three other sub-committees (care, prevention, housing/supportive services). Thus, these sub-committees had much more information to sift through in comparison to the data sub-committee. So, while the data group originally planned to be more of a resource for the other sub-committees, they ended up working more on their own and focusing on how the Dashboard might work, what kinds of information to include, and how to adequately share this information. As David said, “all of that, we had to sort of make most of that up, because we weren’t really sure about what the other committees were going to be coming up with.” Similarly, Peter noted that one member of the prevention sub-committee was very proactive in reaching out to the data group, but “I think it really depended on individuals to do that. It wasn’t that well structured into the process, I think.” So, the data sub-committee, which David claimed was “relatively small and pretty academic,” functioned largely on its own in attempting to determine measures for a set of recommendations that were not yet final.
At the end of the day, Peter says that he often found himself discussing “realms” of data in the sub-committee meetings, and then thinking about what kinds of measures fell within these realms to determine which data sources to include in the Dashboard. As he said in our interview, “I don’t think we did any vetting or…anointing of metrics or measures…that’s just sort of what we were able to pull together” based on what was available. So, as Peter noted, assembling the data sources and metrics included in the Dashboard is more of an “opportunistic” process at this point rather than a process that was determined by consensus in the Task Force. This process involves Peter and his team drawing from the available data and reflecting this data in the site as metrics that align with the priority data “realms” that Peter identified during the Task Force meetings. An example is the HIV care cascade, which Peter believes is a metric “everyone would probably agree on” and which is available state-wide and for individual regions through NY Connects.

So, data transparency from the state facing outward ultimately has its own gaps. While the AIDS Institute clearly made a strong effort to create a Task Force process that was as transparent as possible, this process still was not completely open to the public due to both logistical issues (e.g. high security at the AIDS Institute office in Manhattan) and a meeting structure that sometimes placed sub-committees behind closed doors. As Merry (2011) suggests, measurement and indicators are politically determined tools of power. So, those who decide what to include on the Dashboard and, consequently, what counts as a measure of EtE success wield a significant amount of power in the campaign. Still, the Dashboard is a significant step forward in centralizing data sources and making them easily accessible to the public. And, as demonstrated by Juan and Cynthia’s enthusiasm at the beginning of this chapter, data in the hands of the people has power in itself.
Transparency Type 2: Organizations see and use their own data

On the one hand, state-level transparency around data and related decision making processes is meant to demonstrate accountability and an open working relationship between state government and civil society. A second aspect of data transparency that is key to the Ending the Epidemic campaign involves individual organizations seeing and using their own data for quality improvement. As shown in Chapter 2, Ending the Epidemic relies heavily on providers to take “responsibility” for their individual role in EtE. In order to do this, providers must be able to know how they are performing in relation to the campaign’s goals and to make adjustments when they are not performing well.

As Peter mentioned in relation to the Dashboard metrics, the HIV care cascade seems to be one of the main data tools that EtE organizers are relying on to help the campaign realize its goals. Specifically, the cascade is both a metric that reflects EtE progress over all and a tool that individual organizations are expected to use to track and respond to their own patient populations. Indeed, during his remarks at the July 2015 implementation meeting, Charles King said, “This is my moment to get on my soapbox” as he went on to discuss the importance of the HIV care cascade to EtE work. According to Charles, every agency should have their own cascade and should be working toward viral load suppression (the final step of the cascade) in all of their patients. Participating in the AIDS Institute’s quality improvement program, he suggested, is one way to do this. Further, Charles prompted, “And we should make our cascades public, especially to our consumers and our staff.” In these remarks, one of the campaign’s main organizers specifically pointed out the importance of the HIV care cascade and called on providers to make their own cascades internally transparent (or, “public”) to their own staff and
their patients. This idea was connected to providers engaging in quality improvement work, which is orchestrated by the AIDS Institute from the level of the Department of Health.

As a major data source for Ending the Epidemic, NY Connects also is a key motivator for individual organizations to track and use their own data as a way to contribute to the campaign. In an interview with one of the NY Connects planners, Dale, he told me “it was the cascades that I think gave me the first hint that we had all the information we needed” to end the epidemic. And in his work with NY Connects, Dale said, “We always tell providers, the important thing is that you understand your own data. Because you can’t move forward without understanding your own data.” NY Connects not only requires participating sites to submit data on linkage, retention, and viral load suppression, but this data is then translated into organization-specific (“facility-level”) cascades that are sent out to participating providers. A number of participating sites seem to appreciate these data tools and some sites even generate their own cascade, which they report using for internal decision making. In addition, the cascades sometimes are shared among the whole group at NY Connects regional group meetings, which providers report provokes a sense of competition among them.

In fact, competition is a common theme among AIDS service providers. In a resource-constrained environment, providers already feel the pressure of competing amongst each other for funding on a regular basis. This can also mean competing for patients who bring in more money through insurance payments and/or help providers meet their targets for specific grants. In this respect, comparing data across sites can be very effective for encouraging organizations to improve their quality of care. However, NY Connects really aims to use data to bring providers together around reaching particular targets. As Dale put it:

We kinda lost our way with HIV by forgetting this is also a public health issue. It’s not just the individual person, but it’s the community they exist within…The cascades are
great for saying to people ‘Look, look. This is you. This is your community. This is you. Now what can we do to make this better?’

Thus, in the context of NY Connects the state is turning data around and giving it back to providers to encourage them to make individual and regional contributions to a common goal. However, when the state encourages competition at the same time, it further emphasizes the message of “collective individualism” that arose in Chapter 2. So, while giving providers more access to their own data does promote transparency, it also promotes accountability both internally as well as to other providers and to the state. While this accountability can indeed help to improve quality of care outcomes, in this respect the transparency also serves the interests of a state that needs to monitor its healthcare system.

**What Remains Opaque**

While transparency is a key theme of Ending the Epidemic, there is much that remains opaque when it comes to knowledge management and data. Responding to a PowerPoint slide showing relatively low rates of HIV among women in New York State at the October 2014 metrics meeting, a prominent AIDS activist (Fred) pointed out that there is still a story behind these numbers. Fred noted that domestic (or “gender-based”) violence is still a relevant concern in New York and so, “I hope that some of our success stories…don’t blind us to some sub-populations who still need us.”\(^{19}\) Indeed, Fred’s concern is particularly valid in such a large-scale campaign that depends so heavily on data to drive its success. And a closer look at some of the data driving the campaign reveals major gaps (some of which are acknowledged by the campaign

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\(^{19}\) Many links have been shown between gender-based violence and HIV transmission (see for example: Shannon et al. 2009; Gielen et al. 2007; Dunkle et al. 2004) and we certainly know that gender power dynamics in general put women (both cisgender and transgender) at greater risk for HIV (Farmer et al. 1996). A 2012 snapshot report on domestic violence in New York City shows that women accounted for 79.1% of intimate partner homicide victims between 2001 and 2012 (New York City Mayor’s Office to Combat Domestic Violence 2012).
organizers themselves) as well as places where data interpretation seems to skew in favor of a narrative that privileges HIV prevention among young MSM of color and transgender women.

For all the data that the state, insurers, pharmaceutical companies, and providers have gathered, Ending the Epidemic organizers and participants still recognize there is much that is missing. These data gaps usually form around populations that are generally difficult to reach with HIV services, such as young people and transgender women and men. For example, when discussing PrEP access, Task Force members regularly raised the issue of access for young people who may have difficulty obtaining a prescription for a medication only approved for those 18 years and older, or who may hesitate to start PrEP when their insurance statement of benefits is legally required to go to their parents. The Blueprint includes a recommendation in this vein, GTZ [Getting to Zero] 7: Guaranteeing minors the right to consent to HIV and STI treatment, diagnosis, prevention, and prophylaxis, including sexual health-related immunization. This is a recommendation that minors should be able to consent to HIV treatment and prevent (PrEP) without parental consent and “explanation of benefits” statements from insurance companies should go to the patient (i.e. the minor) rather than the insurance policy holder (i.e. the parents) (New York State Department of Health 2015: 31-32). However, these are only recommendations, and when young people face barriers to accessing services and medications, it is difficult to collect data on their health practices and needs.

There is another major gap in the data around transgender people. As early as the October 2014 metrics meeting, researchers involved in EtE voiced their concern around the dearth of data in this area and a representative from the Department of Health chimed in that the state doesn’t keep data on transgender people. However, this is not entirely true. According to the New York State’s 2012 HIV epidemiologic profile, the HIV/AIDS surveillance system has recently been
changed to allow providers to document a patient’s transgender status, “although in reality very few cases in the surveillance system are labeled this way” (New York State Department of Health AIDS Institute 2013: 61). This is partly because, as Dan O’Connell noted at the July 2015 implementation meeting, transgender women often are captured in the data as men who have sex with men (MSM). A prominent activist in the transmasculine community confirmed this problem to me in a personal email in November 2015. He wrote, “Some common challenges [for the trans community] are…inaccurate data collection (still counting Trans women as MSM). While more attention is being paid to Trans women than before, little to none focuses on Trans males.”

What is most interesting about these two particular gaps in the data is that young people, particularly young MSM, and transgender people receive so much lip service in the Ending the Epidemic campaign. Several Blueprint recommendations specifically address these populations, but the irony is that in a campaign driven by data, no one actually knows how much these particular populations are affected by HIV. Further, in the absence of quantitative data, EtE organizers are willing to believe “anecdotal” evidence that comes from service providers and then use this evidence to direct campaign priorities. In another ironic twist, the state’s 2012 HIV epidemiologic profile notes that the civil society group (the New York State Prevention Planning Group) that advised the report process “was consulted to identify subgroups that were at particularly high risk for HIV/AIDS and would therefore receive special emphasis in the Epi Profile. The two main targeted communities that were identified were young MSM – particularly young black and Hispanic MSM – and women of color” (New York State Department of Health AIDS Institute 2013: 61). Despite having been identified as a population at particularly high risk for HIV, women of color are mentioned far less often in official EtE materials and events than are MSM.
These gaps also beg the question of how the available data is interpreted and used. The Ending the Epidemic campaign focuses heavily on MSM, particularly young MSM of color, and transgender women in its messaging. This is because men aged 13-24 are the only demographic among which newly diagnosed cases of HIV are actually increasing (Ibid.: 27). And when the statistics are broken down by transmission risk, MSM are the only population not trending downward in terms of newly diagnosed cases (Ibid.: 28). Further, men make up a much larger percentage of existing HIV/AIDS cases overall. For example, over 3,700 men are living with HIV/AIDS in Nassau-Suffolk county versus more than 2,000 women, and over 25,000 men are living with HIV/AIDS in Manhattan versus over 5,000 women (Ibid.: 21).

However, if we delve a little more deeply into these numbers, there are some striking disparities. While MSM (including injection drug users) make up a total of about 49% of HIV/AIDS cases among men in New York State, women who either confirmed heterosexual transmission of HIV or were “presumed” to have contracted HIV through heterosexual intercourse make up 76% of all HIV/AIDS cases among women (Ibid.: 20). Racial disparities among newly diagnosed women also are more extreme than among men: in 2010 black women made up over 60% of newly diagnosed HIV/AIDS cases while the next group of women most dramatically affected were Hispanic women who made up approximately 25% of newly diagnosed cases. In contrast, black men comprised over 40% of newly diagnosed HIV/AIDS cases compared to Hispanic men at 30% (Ibid.: 22). These figures point to large racial disparities in HIV/AIDS cases among women, an issue echoed in publications such as the AIDS Advisory Council’s 2005 report “Women in Peril HIV&AIDS: The Rising Toll on Women of Color” (New York State AIDS Advisory Council 2005).
When broken down by age group, women face a sharp increase in new diagnoses between the age group 25-29 (approximately 10% of new diagnoses among women) and 30-39 (over 20% of new diagnoses) while new diagnoses among men increase less sharply from over 15% aged 25-29 to just over 20% in the age group 30-39 (Ibid.). In fact, some of these statistics were reviewed at the October 2014 metrics meeting, where one participant raised a question regarding the discrepancy in age at diagnosis between men and women. At the time, the presenter explained that women tend to be diagnosed younger than men due to pregnancies. So, those who are missed at this point appear later for diagnosis. This points to a prevailing issue in HIV/AIDS work globally; services tend to be directed to women as mothers rather than as women in their own right, thereby undermining the quality of care for women who never become pregnant or who already have children when they contract HIV (Wilcher and Cates 2009; Eyakuze et al. 2008). Further, a forthcoming paper from Braunstein et al. (n.d.) found that women and people of color typically have lower CD4 counts at the time they initiate HIV treatment, indicating that they tend to test and start HIV treatment when they are sicker.

Circling back to Fred’s concern that public health success in New York State will “blind us to some sub-populations who still need us,” and particularly women who may be affected by gender-based violence (GBV), the numbers might tell a slightly different story. On the one hand, some of the disparities that arise within the statistics on women suggest that if, as some organizers claim, the Ending the Epidemic campaign ultimately aims to eliminate health disparities, then it is important to pay attention to women and particularly women of color in this effort. Following Jordan-Young (2011) and Fausto-Sterling (2005), though, perhaps it is necessary to further open up the sex/gender “box” when looking at these numbers. If, for example, evidence points to a strong correlation between violence and HIV transmission among
transgender women (Nuttbrock et al. 2015; Operario and Nemoto 2010) and HIV transmission among cisgender women is largely through heterosexual contact, what is the role of gender-based violence in HIV transmission in New York? Since it is challenging to collect data on transgender populations, who also are at particularly high risk for violence (Stotzer 2009), and there appears to be a dearth of data on the relationship between GBV and HIV in New York, this is a difficult question to answer. Further, to what extent might commercial sex work be implicated in these numbers? As a 2012 report from The PROS Network and the Sex Workers Project points out:

Given that people in the sex trade have been excluded from city and national strategies, it is difficult to measure the HIV/AIDS prevalence rate among this population in the United States, as very little research has been funded to uncover this data. As a result, it is difficult to measure the effectiveness of existing programs targeting people in the sex trade or to scale up effective programs, and therefore difficult to stem the devastation of the epidemic on this population. (8)

This same problem extends to transgender men. As pointed out by the prominent transgender activist quoted above, attention to transmen is particularly lacking in HIV prevention efforts. Indeed, a 2008 systematic review of HIV prevalence among transgender people drew from 29 studies focusing on male-to-female transgender women; only five of these studies included data on female-to-male transgender men (Herbst et al. 2008).

**Discussion & Conclusions**

In conclusion, I revisit Epstein’s discussion of the relationship between social and knowledge hierarchies:

…knowledge hierarchies are rarely ‘accidental’ in their origins: They tend both to build upon and reinforce social cleavages based on other markers of difference—class, formal education, race, gender, sexuality, and nationality. When the power of expert knowledge within a social movement overlaps with other systems of hierarchy, the results can be

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20 For example, the Mayor’s Office to Combat Domestic Violence only issues reports on homicides related to violence in the home. These reports do not include other potentially relevant health information for victims of violence who survive, such as minor injuries, pregnancies, or HIV status.
problematic for the movement, even if the new experts work entirely in good faith for the benefit of all…These considerations suggest the true dimensions of the problem: it is unlikely that knowledge-making practices can be substantially democratized, except when efforts to do so are carried out in conjunction with other social struggles that challenge other, entrenched systems of domination. (1996: 352).

Here, Epstein points to the overlap between social power systems and the power relations of knowledge. What he recognized as “lay experts” in early AIDS activism were largely gay white men who already enjoyed the privilege of being white, male, and often educated. In contrast, those most affected by HIV/AIDS in New York State do not share these privileges. So, with data collection and management playing such a key role in the Ending the Epidemic campaign, the question remains as to how much knowledge has been “democratized” in this process.

Much of the data used in Ending the Epidemic comes from the state, and particularly the Department of Health and its AIDS Institute. In practice, this data is generated on the ground by healthcare workers, many of whom are women and people of color; populations that often already are exploited in the workforce. Among those who participate in NY Connects, for example, many of these workers complain that data generation and submission are time-consuming and confusing in an environment where their time and resources already are stretched very thin. Here, the state is the arbiter of data.

While some scholars point to data collection as a means of state control (e.g. Scott 1999; Foucault 1978) and it is clear that data and measurement enable government management, the picture here is a little more complex. Through EtE, the New York State Department of Health is attempting to give providers greater access to both their own data and that of their peers. On the one hand, this data “transparency” is meant to provoke friendly competition among providers that will encourage them to perform better in the interests of the state. But mechanisms like the Dashboard also provide the public with accessible information and create state accountability to
New York’s citizens. Further, providing data trainings for patients (as mentioned in the Introduction) through EtE-affiliated programs like NY Connects, and then giving these patients access to data opens up more opportunities for meaningful involvement from a wider variety of participants.

Still, at its highest levels, data tends to be managed by the “usual suspects” within the Ending the Epidemic campaign. The data sub-committee of the Task Force was composed largely of academics and most of these, particularly the most active members, were men. This dynamic echoed the October 2014 metrics meeting, where there were very few people of color in the room and most of the participants seated around the main table were men. Even though one activist in this meeting (Tim) appeared at a slight disadvantage due to his age, he still felt confident to argue over a particular modeling method with a participant from the CDC. Later, during the July 2015 implementation event, a fellow activist jokingly referred to Tim as “Dr. Tim,” signifying his acceptance as an expert and a purveyor of knowledge. In this case Tim, a gay white man, was able to cross the boundary into this particular scientific community. In my interview with Christina, a young woman of color and a youth health educator, she was aware of the power that is reserved for those who are more educated. Christina distinguished herself from her colleagues with university degrees, saying “we’re not teachers, we’re educators…We’re trained, but we don’t have degrees on it…educators are trained, but teachers they go to school for it.”

As noted in Chapter 2, the July 2015 implementation meeting also was a place where divisions along the lines of race, class, and gender were strongly felt when a couple of transgender activists of color repeatedly voiced their concerns that they were being left out of the EtE process. This meeting featured one panel on metrics and benchmarks that was jokingly
referred to as “the numbers panel;” all of the members were white. These examples all point to knowledge management at the highest levels that is carried out by people who enjoy racial privileges, and often gender and class privileges as well. Hopefully this picture will change a bit as the AIDS Institute draws more input from population-specific advisory groups to EtE, such as the transgender advisory group, that were formed after the Blueprint was completed.

Further, if measurability equals manageability, then those who control data in turn control what is measured and how. In the context of Ending the Epidemic, this in turn translates to who receives government recognition, resources, and support. And the demographics of those who control data is important because, as outlined in the literature review above, quantitative scientific knowledge has a gender and race component built in. So, a heavy emphasis on numbers to track campaign progress is already an endeavor that carries these power dynamics within it. What is interesting, though, is the willingness among campaign organizers to accept some “anecdotal” evidence as related to certain populations, i.e. young and transgender people. Here, the organizers recognize knowledge “gaps” around these populations and one way in which these populations can gain more legitimacy within HIV/AIDS work in New York State is through greater representation in the numbers. Possible explanations why certain populations garner so much attention in Ending the Epidemic without numbers to back them up are explored more deeply in Chapter 5.

Regardless of why transgender and young people may receive a disproportionate amount of attention in EtE, the relative lack of attention to women of color, who have long been considered a key population affected by HIV/AIDS in the state, is notable. While the state does keep statistics on HIV transmission among women, Ending the Epidemic organizers may be partly motivated by the very lack of data around transgender and young people. Further, women
 make up a relatively small proportion of HIV/AIDS cases overall (though, since transgender people are a very small percentage of the state’s total population, surely they do not make up a large proportion of current infections either). In a nod to the literature on PMTCT programs and access to care for women, it also is worth noting that EtE organizers often proudly refer to the fact that the state recorded no babies born with HIV in 2015; a fact which may convey some sense that the work among women of childbearing age is done.

Yet here is where thinking across and beyond the numbers may make a difference. As noted above, women are by far the most likely to get HIV through heterosexual transmission, although there is little or no data to tell us exactly how this happens. Further, women of color are disproportionately affected among women overall and these women face many of the same structural constraints faced by people of trans experience (e.g. racism, poverty, sexism, violence). While there certainly are good reasons to track statistics separately for cisgender and transgender women, as well as transgender men, this may also be a place where it would be useful to think thematically across data “siloes” to effectively address the needs of these populations. As has long been suggested by prominent anthropologists of HIV/AIDS, perhaps the problem of HIV transmission among all of these populations is best framed as a confluence of gender power dynamics, race, and poverty (Baer, Singer and Susser 2013; Susser 2009; Farmer and Connors 1996). Thinking about data Thematically in this way suggests that it might be most useful to organize campaign data on the Dashboard, for example, as side-by-side or even intersecting visualizations according to these types of themes, rather than by individual population, “risk factor” (e.g. injection drug use, anal intercourse), or key Blueprint targets.

Further, metrics used to measure campaign success should be considered interactionally as well. As Charles King and others pointed out at multiple Blueprint implementation meetings,
Ending the Epidemic will not be a success if the state achieves its goal of 750 new infections per year, but all of these infections are among one population; the numbers must balance out and show an overall reduction in health disparities. Since health disparities occur most acutely at the intersections of marginalized identities (Mullings 2005; Singer and Clair 2003), the metrics used to measure the success (or not) of Ending the Epidemic similarly should reflect these intersections by tracking, for example, rates of HIV transmitted through gender-based violence among black women. In this way, EtE might further bridge the data siloes it aims to eliminate while also tracking health outcomes in a more complex and meaningful way that can address disparities more effectively.
CHAPTER 4 Mobilizing PrEP: A Marketable Product or a Healthcare Tool?

This chapter analyzes the mobilization of pharmaceuticals across sectors in the Ending the Epidemic campaign. As one of the three main pillars of EtE and a relatively new technology (the HIV drug Truvada was only approved as pre-exposure prophylaxis in 2012), the roll out of pre-exposure prophylaxis (PrEP) on a large scale virtually requires all sectors involved in the HIV response to work together. Indeed, prior to announcing the campaign the state had to negotiate prices with Truvada’s manufacturers under the assumption that the Department of Health would have to provide PrEP for free or at very low cost to many who qualify. In addition, a number of activists and service providers in New York City have been meeting as the NYers4PrEP Task Force for the past several years to coordinate messaging, service delivery, and learning across the city. However, rolling out PrEP on a large scale across the state presents multiple challenges from the systemic level (e.g. coordinating access to medication through the Department of Health’s new PrEP Assistance Program) to the level of the clinic and reaching potential patients. These challenges are not only logistical, but intersect with historical patterns of inequality that have made general healthcare more accessible to certain populations than to others.

I examine PrEP mobilization through this lens of inequality in both this chapter and the next (Chapter 5). In this chapter, I take a broad view of how different kinds of identities are mobilized (or not) to make PrEP more accessible and available across the state. While people living with HIV/AIDS have been able to organize and mobilize as a single community in the past to demand treatment, HIV-negative people do not share this identity. And indeed, they are not even sick. In this context, how is PrEP mobilized, and how are the people themselves mobilized to access a new method of HIV prevention? What does this look like across lines of gender, race,
and class? Chapter 5 takes a deeper look at the ways in which PrEP is marketed to different populations using a language of “choice.” This language has long been associated with women’s reproductive health, and particularly with abortion and the “right to choose.” However, in this chapter I examine the language of choice as a device that exacerbates inequalities when it prescribes who is or is not supposed to choose PrEP.

Following Escobar’s (1994) theory of “technoscapes,” we might suppose that new technologies bring forth their own particular social worlds. Or, as Marcus (1995b) proposes, that “technoscientific imaginaries” emerge among those involved in the science and technology industries. In a scientific landscape filled with competing viewpoints and priorities, these imaginaries allow scientists to reconcile social changes in such a way that it is possible to continue their work. Certainly, imagination may be a key component in connecting a disparate community (see Anderson 2006). However, the goal for PrEP mobilization through Ending the Epidemic isn’t necessarily to create a community of users, but more simply to link potential users to information that will hopefully bring them to healthcare and, if appropriate, to PrEP.

For much of the history of HIV/AIDS, mobilizing pharmaceuticals has been bound up with PLHA self-identifying with the virus and becoming part of a community through this identification (Robins 2006; Nguyen 2002). Historically, those who started HIV treatment relatively early have become leaders in treatment activism due to their extensive experience and knowledge. Nguyen et al. (2007) call this “a kind of implicit process of producing activists through access to treatment” (S34). Although Nguyen et al. conducted their research in South Africa, they fail to make a connection here between historical privilege along the lines of race and class, and early access to HIV treatment. These historical patterns are reproduced among activists as those already in privileged positions assume leadership roles. However, in a later
article, Nguyen et al. point to the dangers of recreating inequalities through a move to re-medicalize HIV prevention with new technologies like Treatment as Prevention (TasP). Re-medicalization, they warn, may draw attention away from economic and gender inequalities in favor of biomedical solutions (Nguyen et al. 2011).

Certainly, medicalization often is associated with reproducing patterns of inequality from the medicalization of child birth (Van Hollen 2003; Martin 1987) to social conditions like homelessness (Lyon-Calio 2000). Drawing together the relationship between activism, inequality, and pharmaceuticals, Biehl (2009) suggests that public health becomes “pharmaceuticalized” in the context of a neoliberal market state that privileges the demands of organized interest groups claiming to represent civil society (11). Indeed, claiming the rights of citizenship by seeking medical treatment is nothing new (Nguyen 2007; Petryna 2003). But Biehl points out that, in attending to these needs, the state neglects “…broader public needs for life-sustaining assistance--in the domains of housing, economic security, and so forth. To be ‘seen’ by the state, people have to join these groups and engage in lobbying and lawmaking” (2009: 11). On the one hand, drugs stand in for comprehensive public healthcare. On the other, those with the greatest access to good care and good drugs are those who already are privileged enough to organize and ask.

In short, pre-existing inequalities can easily be reproduced through pharmaceuticalization just as through medicalization. These assertions certainly are corroborated by Petryna and Kleinman (2006), who point to the role of pharmaceuticals in reproducing inequalities through a globalized marketplace. This reproduction of inequality occurs in myriad ways, from pharmaceutical research and development (Abadie 2010; Petryna 2006) to the way drugs are marketed (Roberts 2011; Elliott 2010; Martin 2007) and distributed (Outterson 2004; Joseph
2003). This is especially true of the global market in AIDS drugs, which exacerbates the social inequalities that put many at risk for contracting HIV in the first place (Biehl 2009; Halliburton 2009; Heimer 2007).

Since Truvada can be used both to treat HIV and to prevent it, this drug blurs the line a bit between treatment and prevention. As a result, it isn’t quite correct to liken mobilization around PrEP to historical activism around access to HIV treatment. Instead, we might think of PrEP more as a vaccine. As public health projects associated with state power (and possibly coercion), vaccines have caused controversy among those who believe they ultimately cause disease rather than preventing it (Sobo 2015; Kaufman 2010), or who see vaccination as a direct threat from a mistrusted postcolonial state (Giles-Vernick et al. 2016; Feldman-Savelsberg et al. 2000). Similar to these postcolonial fears, in the U.S. we can draw a parallel to a history of racism in the medical system that continues to resonate with people of color seeking healthcare (Thomas and Quinn 1991).

Due to its association with sex and sexuality, PrEP access and mobilization may best be compared to recent debates around the human papillomavirus (HPV) vaccine. Although HPV affects both women and men, certain strains can cause cervical cancer. The vaccine’s manufacturer, Merck, therefore chose to market the vaccine (Gardasil) as cancer prevention in an effort to downplay the vaccine’s association with a common sexually transmitted infection. As such, Gardasil originally received FDA approval for use only in women and girls, creating the impression that HPV is primarily a women’s disease (Pisciotta 2012; Mara 2010). Gottlieb (2013) describes the “patient-advocate-consumer nexus” she observed around Gardasil mobilization in California. According to Gottlieb, since restrictions have been placed on pharmaceutical companies that limit their ability to market to physicians, these companies have
become increasingly dependent on patients acting as both advocates and consumers. In the context of Gardasil, Gottlieb suggests that an “apolitical activism of awareness” has developed as a new form of patient activism (343).

Following Gottlieb’s characterization of activism carried out by people simultaneously acting as patients, advocates, and consumers, it is noteworthy that framing patients as “consumers” is a common refrain in the Ending the Epidemic campaign. Generally, this language is meant to put patients in positions of greater power in relation to medical “providers,” since calling patients “consumers” gives the sense that they exercise greater choice in the free market (Ibid.; Applbaum 2006). As Gottlieb writes, “Physicians become ‘providers,’ and patients are transformed into healthcare consumers, replete with the expectations of consumer behavior and choices” (2013: 336). In addition to AIDS activism, the language of medical consumerism similarly shows up often in other health movements, such as breast cancer awareness, where the actual consumption of designated pink products is meant to contribute to the cure (Jain 2007; King 2004).

However, as Maskovsky (2000) points out, free market consumerism tends to hide the power relations that put certain people in a greater position to “consume” than others. While Maskovsky is writing about the Medicaid marketplace, this is no different in the case of pharmaceuticals. However, in the pharmaceutical marketplace, patient “consumers” sometimes can be mobilized to advocate on behalf of certain drugs, thereby doing the job of pharmaceutical companies who are limited in their ability to market their products directly to physicians. While AIDS activism historically has focused on drug development and access to HIV treatment, and this activism has been led by those most affected by HIV, PrEP mobilization presents a slightly different picture. In this case, the “well” must be rallied to seek out PrEP. When those who may
need PrEP the most are already marginalized and unlikely to seek any form of healthcare, how do those involved in Ending the Epidemic facilitate widespread access to this drug? Who counts as a desirable “consumer” of PrEP and what are the implications of targeting certain populations over others?

**The Story of PrEP**

**The Evidence Base**

As discussed briefly in Chapter 1, two new HIV prevention options came on the scene in 2010 that had the potential to end decades of reliance on condoms. That year, the HPTN 052 study proved that early HIV treatment could act as prevention (known as Treatment as Prevention, or TasP). In other words, when people living with HIV/AIDS are virally suppressed and take their medication regularly, they are highly unlikely to transmit HIV to their partners (Cohen et al. 2011).\(^\text{21}\) In the same year, the iPrex trial showed that the HIV treatment drug Truvada (a combination of emtricitabine and tenofovir) also could be used to prevent infection among men who have sex with men (Grant et al. 2010). These results were then corroborated among people who use drugs and heterosexual couples (Kachit et al. 2013; Baeten et al. 2012), and the U.S. Federal Drug Administration approved Truvada as pre-exposure prophylaxis (PrEP) in 2012.

Unlike HIV treatment, which should be lifelong following a positive diagnosis, HIV prevention is sometimes “seasonal” or it may occur in short spurts following an incidence of possible transmission. For example, a serodiscordant couple (in which one partner is HIV-

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\(^{21}\) Some studies proving PrEP’s efficacy, such as the Partners Demonstration Project (Baeten et al. 2015) have used TasP in combination with PrEP to prevent transmission between sexual partners. However, because TasP is a prevention method controlled by people already living with HIV and this chapter explores the mobilization of drugs for those who are HIV-negative, a deeper discussion of TasP is outside the scope of this discussion.
positive and the other is HIV-negative) may wish to conceive and so they may have unprotected sex only during this time. Or, a person who has just ended a stable partnership may wish to protect her/himself while engaging with multiple sexual partners. Since its approval in the U.S., several major studies have set out to explore the efficacy of event-driven or seasonal PrEP, as well as different patterns of adherence. The results of several of these studies were presented at the 2015 Conference on Retroviruses and Opportunistic Infections (CROI) in Seattle, prompting Rafael, a policy expert at a New York City-based advocacy organization, to refer to the conference as “PrEP’s Bar Mitzvah…or maybe Quinceañera.”

These studies of irregular PrEP use found that the drug still can be effective when taken immediately before and after unprotected sex, or even if taken at minimum four times per week (as opposed to daily) (McCormack and Dunn 2015; Molina et al. 2015). While these studies were important for proving PrEP’s efficacy under different conditions, during a meeting of PrEP providers and advocates in New York City, Rafael noted that “both studies were pretty white.” Like the original iPrex study, these studies also focused on men who have sex with men.

In contrast, much of the evidence base around PrEP for women, particularly in the form of a vaginal microbicide, has been less promising. While the original CAPRISA microbicide trial showed promising results (Abdool Karim et al. 2010), follow up studies have had trouble proving efficacy due to problems with adherence among trial participants. While barriers to adherence appear to have been related to structural inequalities like gender, poverty, and stigma, study designs haven’t necessarily accounted for such barriers and researchers sometimes have blamed the women participants for their lack of adherence (Rees et al. 2015; Marrazzo et al. 2015; Van Damme et al. 2012). There also has been ongoing investigation of a rectal microbicide through the MTN-017 study, which announced some success with product safety
and acceptability in early 2016 (Cranston et al. 2016). However, the study has not yet produced results on the microbicide’s efficacy. Despite the fact that cisgender women may well engage in anal sex, this study focuses on MSM and transgender women.

One study that has addressed women and men at the same time and also shown very high efficacy is the Partners Demonstration Project. Conducted in Kenya and Uganda, preliminary reports from this study showed a 96% reduction in projected HIV incidence when serodiscordant heterosexual couples were enrolled in a program that combined PrEP for HIV-negative partners with a simultaneous transition to treatment for their HIV-positive partners (Baeten et al. 2015). Since treatment can act as prevention for HIV-negative partners (Cohen et al. 2011), this study essentially combined pharmaceutical prevention methods for both partners in a serodiscordant relationship. While the results appear to be impressive, it is worth remembering that, because couples had to jointly enroll in the study, those who participated may have been especially inclined to care for their own health and the health of their partner.

**PEP: PrEP’s “Older Sister”**

In 1995, the CDC reported that some of the same drugs used to treat HIV infection also could be used to prevent infection when taken in very high doses shortly after exposure to the virus (U.S. Centers for Disease Control and Prevention 1995). This method of prevention, called “post-exposure prophylaxis” (PEP), initially was aimed at healthcare workers who had been accidentally exposed to HIV through their work. PEP went into widespread use in the healthcare field shortly after these findings were released; the UK released a protocol on PEP use in hospitals in 1997 (United Kingdom Department of Health 1997) and a 2000 review of PEP protocols throughout the European Union found that, since 1998, 20 out of 27 European countries had developed their own national guidelines on PEP, while three had adopted the CDC
recommendations, and only four countries had no protocol in place (Rey et al. 2000). Shortly after the 1995 CDC report came out, researchers began to publish evidence for “non-occupational” PEP (nPEP), demonstrating that PEP also could be used to prevent HIV infection following sexual exposure or exposure through injection drug use (Drezett 2002; Harrison et al. 2001; Kahn et al. 2001; Katz and Gerberding 1997). These findings were particularly relevant to: victims of sexual assault (Bamberger et al. 1999), including children (Babl et al. 2000); men who have sex with men (Schechter et al. 2004; Kalichman 1998); and injection drug users (O’Connor 2000). Presumably, sex workers would also benefit from PEP, but there appears to be a dearth of literature on PEP use among commercial sex workers. This may be due to the challenges of conducting research among populations that engage in potentially stigmatized and illegal behavior (Shaver 2005). Or, it may reflect larger trends in academic health research that tend to neglect those already neglected (Boehmer 2002). To be sure, though, women and men who engage in sex work may well engage in other activities already captured by the research on PEP, such as anal sex and drug use, and evidence points to high rates of gender-based violence among sex workers as well (Shannon et al. 2009).

However, one of the main challenges with producing evidence on PEP, and particularly nPEP, is that medical ethics basically preclude researchers from conducting clinical trials according to the gold standard randomized controlled trial method; if a person likely has been exposed to HIV and they are not given access to a method that has been proven effective under other circumstances, this constitutes a breach of ethics. A 2007 systematic review of PEP effectiveness, for example, identified no randomized controlled trials of PEP and the authors concluded that a placebo-controlled study likely will never be conducted due to ethical and practical considerations (Young et al. 2007). Perhaps for this reason, PEP never achieved the
cache that PrEP now enjoys. Charles King suggests this also may be due to PEP’s limited use value without PrEP: “We had post-exposure prophylaxis, but there was tremendous reluctance” to make this available other than for rape. “But when you got people to think it through, it really was that we didn’t have the other side of the coin, the PrEP side of the coin.” Despite the nature of the evidence around PEP, it still has become a standard of care in the U.S., and PrEP has as well (Smith et al. 2005).

Emily runs one of New York State’s most popular PrEP training programs for providers. She also was one of the most vocal advocates for including PEP in the Blueprint each time PrEP is mentioned. Emily says that she met with the Assistant Commission of Health “on a Sunday at his gym…and I was like ‘We need to put nPEP in where we can.’” The two were successful and in the Blueprint section dedicated to PrEP, each of the four recommendations specifically addresses both PrEP and nPEP. However, when I asked Emily about PEP during an interview, she said:

So, we started to weave in PrEP [to the training program] after it was FDA approved, but we were still kind of in the middle of this flurry of people still not even knowing how to implement PEP into their practices…I would pitch PrEP and pitch it and pitch it and pitch it, and they were like “Eh, well…” It was too new…What if it really isn’t safe and effective…what if Robert Grant [the Principal Investigator of iPrex, the study that proved PrEP’s effectiveness] didn’t really know what he was talking about. But eventually, the pendulum completely went. Now we rarely get PEP requests…cuz I look at PEP as the older sister. She was really popular, she was the older sister. Maybe she was the cheerleading captain, but then her little sister PrEP came around and everybody was like “Oh, she’s cuter and younger. So now I’m interested in her.”

Similarly, during a meeting of the NYers4PrEP Task Force (discussed further below) in May 2015, the meeting’s facilitator suggested that, because there is no way to adequately test PEP, the group should think of this technology as a “sister prevention modality” to PrEP.

Indeed, while Emily suggests that PrEP is becoming more popular, PEP and PrEP are regularly used in combination. Some of the studies used to prove PrEP’s effectiveness (e.g.}
Molina et al. 2015) also have offered PEP to trial participants who may have forgotten to take their daily (PrEP) pill and were subsequently exposed to HIV. Further, I have heard several Task Force participants repeat the line, “PEPpers become PrEPpers.” In other words, patients who repeatedly ask for PEP (an emergency prevention method) may be good candidates for PrEP (an ongoing prevention method). So, in the world of pharmaceutical prevention for people who are HIV-negative, PrEP and PEP really work together.

Interestingly enough, while PrEP is certainly an EtE campaign buzzword, it is not yet fully on physicians’ radars in the real world. In addition to in-person trainings, Emily’s program also runs phone services so that physicians can call in with questions around PEP and PrEP. Since the program began collecting data in 2014, Emily reports that most of their calls have been around PEP, not PrEP. She attributes this disparity to PrEP’s relative newness, while PEP has been around for awhile and so more physicians are aware of it.

Since PEP has been available much longer than PrEP, people at high risk for contracting HIV may be more aware of it as well. In March 2015, while visiting a biotechnology company that purports to be working on a cure for HIV, I met Carrie. Carrie is a transgender woman of color and she also is a commercial sex worker. In Chapter 1, the reader was introduced to Carrie as she became embroiled in a fight over PrEP’s effectiveness at the April 2015 Blueprint launch event. Indeed, Carrie is passionate about HIV prevention and during the course of our day she told me a bit about the alternate plan she devised to end the epidemic that focuses on PEP. Carrie claims that she has been exposed to HIV on more than one occasion through her work and each time PEP has prevented her from contracting the virus. So, she is on a mission to educate more people, and particularly her fellow trans women and sex workers, about the benefits of PEP. Unfortunately, due to both of our erratic schedules, I never was able to secure a copy of Carrie’s
plan, but after hearing her speak in a couple of different forums, there is no doubt in my mind that Carrie is a firm believer in PEP as a cornerstone of Ending the Epidemic. Given that the EtE campaign focuses so heavily on transgender women, and particularly those of color, Carrie’s opinion is clearly noteworthy.22

**How PrEP Became Part of Ending the Epidemic**

When Charles King tells the story behind Ending the Epidemic, he describes negotiating drug prices with pharmaceutical companies before the campaign could officially move forward. According to Charles, he met with the head of NY State Medicaid where they “did the math” and realized that the current structure of paying for HIV treatment would “break the bank” if they got more people on medication as part of an initiative to end the epidemic. This led to the idea of negotiating volume discounts with the pharma companies. Speaking of a conversation with the head of New York State Medicaid, Charles said, “Finally in November [2013], he got approval to let me reach out to Gilead [one of the major HIV pharmaceutical companies producing Truvada].” By early 2014, Gilead had agreed to volume discounts with the state and 85% of the major pharmaceutical companies that produce drugs for HIV had signed on by April. The director of the AIDS Institute, Dan O’Connell, confirms Charles’s story and says these volume discounts were one of the major pieces that allowed Ending the Epidemic to move forward:

> There were significant financial implications…in order to get to where we say we want to get to…have to make sure that everyone that should be on ARVs [antiretrovials] is on ARVs…a very expensive proposition…What was going on behind the scenes…the state would be trying to negotiate out with the pharmaceutical companies some kind of price break…we wanted pharmaceutical partners, we wanted healthcare partners…we wanted everyone to be on board…

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22 While the Blueprint generally refers to “nPEP,” I would suggest that in the case of someone like Carrie, it should be referred to as PEP (occupational), rather than nPEP (non-occupational) in order to acknowledge the legitimacy of commercial sex work as a profession.
Once these things all fell into place, Governor Cuomo was able to announce the campaign in June 2014.

The relationships formed between state, civil society, and major pharmaceutical companies also paved the way for PrEP to play a major role in the campaign. As Mark Harrington noted in our interview, EtE always was meant to capitalize on recent scientific findings around PrEP and Treatment as Prevention (TasP). Therefore, when the AIDS Institute asked for an outline of an initial plan from the activists, providers, and researchers involved early on, they developed five key points:

1. Fourth generation testing;
2. Combination prevention (PEP, PrEP, TasP);
3. Treatment for all and high rates of viral load suppression;
4. Housing and supportive services;
5. Community ownership and political leadership.

Stephanie, who was involved in these early discussions, confirms that there were five points to the original Ending the Epidemic plan, which were then condensed into three points by the Governor’s office. When Governor Cuomo whittled the original five-point plan into the three points that concentrate on expanding HIV testing, increasing linkage to and retention in care, and improving access to PrEP, Stephanie said, “actually he elevated PrEP probably even more than we did…in a kind of odd way…in a great way.” In fact, Stephanie reported that PrEP access was a major concern among activists involved in getting EtE off the ground. She thinks PrEP was included as one of the three final pillars of the plan because “communities [were] insisting on it.”

PART I: Mobilizing PrEP at the Structural Level in New York State

According to the Ending the Epidemic Blueprint, “Successful statewide implementation of PrEP requires collaboration among clinical providers, HIV testing programs, primary prevention programs and support services providers” (New York State Department of Health
Indeed, state and city governments have done a lot to facilitate PrEP access, but advocates and service providers have taken up the call with gusto. While some have joked that “putting Truvada in the water” is the best way to roll out PrEP across New York State, many have capitalized on an outpouring of resources from the State and New York City to educate other providers, collaborate on research projects, and raise public awareness around PrEP.

The Ending the Epidemic Task Force: Prevention Sub-Committee

Since facilitating access to PrEP is one of the three main pillars of the Ending the Epidemic campaign, the EtE Task Force was specifically structured to develop recommendations related to PrEP for the Blueprint. As described in Chapter 1, the Task Force was divided into four sub-committees. The Prevention sub-committee, which received the largest number of recommendations from the online public survey, further divided into three thematic “sub-sub-committees” in order to adequately handle the volume of material. One of these “sub-sub-committees” focused on PrEP, one on HIV testing, and Damian (one of the sub-committee’s co-chairs) characterized the last saying, “I don’t wanna say others, but I’ll say additional concerns or additional issues…”

As noted in Chapter 1, participants tended to express some confusion around how the Task Force was formed, which may have had to do with the secretive nature of the process until the full list of participants was publicly released the day of the first meeting. In our interview, Emily speculated that the AIDS Institute may have waited to release the list until the last minute, because they anticipated an outcry from individuals and organizations who felt they had been left out. Indeed, inclusion and representation have been a particularly relevant issue in the field of HIV/AIDS for much of its lifetime (Epstein 1995). However, upon seeing the Task Force list for the first time, Emily recalled her strong reaction to the inclusion of a representative from Gilead:
And so we went through the list…and then I got to the Gilead rep and I was like ‘This is fucking bullshit.’ You mean to tell me that you gave a coveted seat to a pharmaceutical representative? I am sure there is politics involved, but this is not the space. I mean, why can’t they just come and listen like other people who didn’t get appointed. I’m like ‘I don’t want them informing in any shape or form this guidance document.’ That is not free of conflict of interest…it’s not just about PrEP. They make meds that treat HIV and Hep C. I kinda blew a gasket on the train.

Then, Emily discovered that the Gilead representative had been assigned to the Prevention sub-committee and that he was the only medical doctor working with Prevention (most of the doctors on the Task Force had been assigned to the Care sub-committee): “When you work for a pharmaceutical company, you are no longer a medical doctor to me. You’re a sales rep. You’re selling drugs…” So, she called Demetre Daskalakis and said, “‘You know we’re going to be talking about PEP and PrEP a lot’…I said, ‘I need a real medical provider in that room.’” Demetre, who had been assigned to the Care sub-committee, assured Emily he had already spoken with Dan O’Connell and said, “‘I’m moving to prevention, just so you know.’” According to Emily, “He [Demetre] didn’t ask him [Dan], he just told him…These are all prescription interventions, you need to have one of those people [doctors] in the room…”

Here, Emily expresses her dismay at the inclusion of a pharmaceutical representative on the Task Force, let alone on the sub-committee that would be issuing official Blueprint recommendations related to his company’s product. However, her story also illustrates how she and another prominent Task Force member acted quickly to address this imbalance. In my interview with Demetre Daskalakis, he also shared with me that he was the one who “compiled and ‘made pretty’” the Blueprint section on PrEP, suggesting that he was able to exert quite a bit of influence in the process. Still, the final Blueprint document includes a specific reference to Gilead (the only manufacturer of Truvada to date, though the FDA recently approved the drug in generic form (Ryan 2017)) and specifically directs readers to Gilead’s website. The introduction
to the section on PrEP notes, “NYS Medicaid, along with most insurance plans, covers the only currently FDA-approved PrEP medication, Truvada®. Uninsured individuals may receive Truvada® through the Gilead patient assistance program: (https://start.truvada.com/)” (New York State Department of Health 2015: 22).

**The Ending the Epidemic Task Force: The Blueprint**

As noted above, the final Blueprint recommendations on PrEP reflect a broad range of input and a holistic view of PrEP as part of a larger healthcare continuum. As written in the Blueprint:

PrEP is a targeted biomedical intervention to facilitate ‘healthcare as prevention,’ a six-pronged intervention for people who are HIV-negative and at high risk for infection. The intervention includes a once daily pill; periodic HIV testing; periodic STD screening; counseling about the use of condoms to prevent STDs; education about harm reduction options; and, counseling to promote adherence to the once-a-day PrEP medication (Ibid.).

Further, following Emily’s advocacy, the recommendations consistently refer to both PrEP and PEP. These include: “Undertake a statewide education campaign on PrEP and nPEP;” “Include a variety of statewide programs for distribution and increased access to PrEP and nPEP;” “Create a coordinated statewide mechanism for persons to access PrEP and nPEP and prevention-focused care;” and “Develop mechanisms to determine PrEP and nPEP usage and adherence statewide” (Ibid.: 23-24). So, in addition to framing PrEP as part of a more holistic approach to healthcare, the Blueprint recommendations take a broad view of how best to facilitate PrEP access across the state, ranging from an education campaign to mechanisms for distributing the drug and measuring access. This falls in line with the tone of the Blueprint overall, which is meant to provide general guidelines rather than taking a more prescriptive approach. As Demetre Daskalakis noted in our interview, “I think what we wrote for PrEP for instance was very ‘Do x, do y, do z,’ and what came out was an extract…that allows x, y, and z to be there, but also allows
for a, b, and c…” So, while the Prevention sub-committee offered more concrete recommendations, as AIDS Institute staff wrote the final version of the Blueprint they made these recommendations more general. Demetre ultimately believed this was a useful approach, since the original recommendations may have been more appropriate to New York City, while the more generalized final version makes the document accessible to upstate providers.

One way in which the Blueprint section on PrEP does get very specific, though, is in its references to target populations. The Blueprint states that pilot programs and access to PrEP should be enhanced in areas most likely to reach “eligible individuals including transgender men and women, women of color, HIV-negative sexual and needle sharing partners of PWH [persons with HIV], and MSM” (Ibid.: 22). It goes on, “As an example, MSM remain disproportionately impacted by HIV/AIDS with the least reduction in new infections compared to other key populations” (Ibid.). Thus, like much of the rest of the EtE campaign, the Blueprint acknowledges a number of populations that might be eligible for PrEP, but suggests that MSM are an especially high priority by calling attention to this group in particular.

PrEP Policy: City and State

At the level of policy and funding, both State government and New York City’s Department of Health and Mental Hygiene (DOHMH) have put significant resources into expanding PrEP access. According to Demetre Daskalakis, New York City has done PrEP “detailing” with about 1,700 providers, teaching them how to administer both PrEP and PEP. Prior to the “Play Sure” campaign that promotes combination HIV prevention, the City also has run a media campaign that specifically focuses on PrEP. In addition, PrEP has been incorporated into pre-existing City-run programs, such as NY Knows. Detailed in Chapter 2, NY Knows originally aimed to organize providers in New York City to work together to improve HIV
testing access and uptake. Since the launch of Ending the Epidemic, NY Knows has incorporated PrEP into its framework as a service that links well with HIV testing. As a result, NY Knows has become a “technical assistance group” for providers around the City who have questions about PrEP.

Indeed, Dr. Rivera, one of the HIV specialists at NYU Lutheran Medical Center says that she feels her clinics have received plenty of resources for PrEP implementation from the City.

Dr. Rivera said:

I mean, the city has been phenomenal about providing resources. They’ve done tons of trainings. They have sent PrEP representatives to most clinics, particularly the ones that are doing HIV care, to talk to them about their PrEP program. They have very easy to use algorithms and patient education for clinicians. There’s a lot of investment...there doesn’t feel like a lack of resources if a clinic or hospital is interested in starting PrEP.

Further, Dr. Rivera noted a PrEP referral service connected to the City’s general information phone line (311) has resulted in at least 10 referrals for her clinic. She noted, “it’s not a lot, but it is definitely, you know, that’s been within the last year. So, I think that’s a significant factor” contributing to increased PrEP use in her clinic.

Ultimately, Dr. Daskalakis said that New York City will be working to create more integrated models of care that use PrEP as a way to bring more New Yorkers into healthcare. For example, the “PrEP network triads,” which will bring together an HIV testing venue, a community-based organization, and a clinic to “deliver people into care.” Dr. Daskalakis describes this program as “very ‘navigator-ish’ and ‘peer-ish’ and all that stuff,” suggesting that this model is meant not only to bring patients into care, but to engage them more deeply and retain them in the healthcare system. According to Dr. Daskalakis:

PrEP is a major part of our strategy and it’s blending a bit in with testing and blending a bit in with just general care…models of care connectivity and retention that we’re using for HIV are models that we’re going to try to adapt for PrEP. Our shtick is that we think this status situation is silly – HIV-negative, HIV-positive – when everything is identical.
So, our strategy in New York City is to take this to a status neutral place…everything is the care of people and biomedical is a piece of it, but care isn’t all just biomedical, but we have the ability to deliver people to these venues where they could connect to some services that could keep them healthy…

The City’s strategy, then, is to treat PrEP as an integrated piece of a larger strategy that is meant to bring people into healthcare, regardless of HIV status. This is an ongoing theme throughout the EtE campaign that is perhaps best reflected in a comment from an ACT UP member at the October 2014 metrics meeting: ACT UP: “The best thing we can do for prevention is enrolling people into care.”

However, New York City’s Department of Health and Mental Hygiene has drawn the ire of activists by falling short on one piece of this strategy. While Dr. Daskalakis told me that the City was planning to launch a CDC-funded program to “navigate people into PrEP” in City-run STD clinics, the STD clinic in Chelsea, which is one of the most active in the city, closed for a two-year renovation starting in March 2015. This closure provoked extensive protests and a town hall meeting at The LGBT Center led by ACT UP and the Treatment Action Group to discuss the impact of the Chelsea clinic closure on Ending the Epidemic in New York City. Echoing the vision that Demetre Daskalakis laid out for me in our interview, the flyers that ACT UP distributed at the September 2015 town hall meeting read:

With STD Clinics as a model, every testing site in the state could one day become a portal to long-term care for all. This makes the Ending the Epidemic effort a broad public health measure, the best hope for linking many individual New Yorkers from the state’s underserved communities to a lifetime of the kind of care that improves lives.

The flyer goes on, “NYC’s Bureau of STD Control, which operates the city’s STD clinics, has amassed a solid record of failure that dates back many years. How can we trust the Bureau to oversee such an important piece of Ending the Epidemic?”
The Chelsea clinic closure is noteworthy, on the one hand, for what ACT UP rightfully points out as a disconnect between official city policy and actual practice on the ground. On the other hand, Chelsea has long been known as a neighborhood largely populated by gay white men. While this neighborhood has some of the highest rates of HIV infection in New York City, it also has one of the highest rates of linkage to healthcare after an HIV diagnosis (CUNY School of Public Health). This statistic suggests that people in the neighborhood living with HIV/AIDS have adequate access to healthcare and are adherent to their treatment. As one doctor who practices in the Bronx observed during a NYers4PrEP Task Force meeting, New York City’s Community Health Survey shows that, among men, those who identify as gay have the highest access to healthcare in the city. It is perhaps noteworthy, then, that the Chelsea clinic is within walking distance of The LGBT Center on 13th Street. However, we know that men of color who have sex with other men are less likely to identify as “gay” than their white counterparts (Miller et al. 2005). So, the Chelsea clinic renovation may indicate a privileging of this population in terms of sexual healthcare; when will STI clinics in Harlem and the boroughs be renovated, for example? Further, although ACT UP’s flyers note that the Chelsea clinic is the most frequently used STI clinic run by the city, the strong reaction provoked among ACT UP and TAG members feels a bit like the AIDS activism of old in which gay white men already have the power and resources to defend their interests, and put these power and resources to dramatic use.

At the state level, one of the most powerful drivers of change is money. Over the past few years, the New York State Department of Health has rolled out funding mechanisms for PrEP “navigators” at the clinic level, as well as PrEP trainings for service providers. And, as a presenter at the May 2015 meeting of the AIDS Advisory Council’s Ending the Epidemic sub-committee noted, DSRIP (the New York State Medicaid re-design described in Chapter 2) also
includes a mechanism for PrEP outreach to uninsured or low/non-utilizing Medicaid patients in the name of “patient activation.” Further, at the September 2015 sub-committee meeting, a consultant who is assisting the state with the DSRIP process suggested that one way to increase PrEP uptake would be to incorporate it into the Medicaid payment structure as a fee for service option. This would encourage providers to put more people on PrEP if they know they will be reimbursed for this particular service.

While the DSRIP process is still playing out, perhaps one of the most powerful and explicit funding shifts has been the creation of the PrEP Assistance Program (PrEP-AP) in early 2015. Modeled on the state’s AIDS Drug Assistance Program (ADAP), which provides financial assistance for HIV treatment, PrEP-AP is meant to cover the costs of basic primary healthcare related to PrEP use. According to Fred, a prominent AIDS activist, the idea for PrEP-AP came from ACT UP and their concern that people who are undocumented and/or under-insured would have trouble accessing PrEP without insurance to cover the hefty cost of care. Indeed, according to the New York State Department of Health’s HIV care website (www.hivguidelines.org), taking PrEP requires extensive testing as well as regular maintenance visits to a healthcare provider. Prior to obtaining a prescription, in addition to basic metabolic testing, a prospective patient must undergo HIV testing (to confirm that s/he is HIV-negative), testing for other sexually transmitted infections (STIs), testing for Hepatitis A, B, and C, and pregnancy testing where appropriate. Once a patient has been confirmed HIV-negative (which may or may not happen on the day of testing depending on the type of test used and the facility at which it is performed) and appropriate for PrEP, s/he can obtain a 30-day prescription. After 30 days, the patient must return to the clinic for a follow-up visit and a new 60-day prescription. Subsequent visits are then scheduled for 3 months, 6 months, 9 months, and one year after the date of the
original prescription to check in with the patient and perform regular HIV tests. In short, PrEP is an intensive commitment on the part of both patient and provider, and it has the potential to be very costly.

At the February 2015 NYers4PrEP Task Force meeting, a Department of Health staff member gave a presentation outlining PrEP-AP’s main goals and areas of coverage. PrEP-AP is a fee-for-service model that reimburses registered providers for costs related to PrEP prescription and maintenance, and then bills insurance companies to recoup the cost. Financial eligibility for patients was set at 435% of the Federal Poverty Level, which is about $50,000/year. In its early stages, the program aims to cover a patient’s initial visit to the doctor, the prescription visit, and also quarterly follow-up visits. It also will cover some services like a Meningitis vaccine, STI and Hepatitis screening. However, PrEP-AP does not cover the cost of any drugs, which includes not only Truvada for PrEP, but also any treatment recommended for STIs or Hepatitis found in screening. Other services, such as Gilead’s patient assistance program, are expected to fill in these gaps.

While PrEP-AP is still new and seems to make a good faith effort to close the gaps left by insurance companies around PrEP access, one New York City provider, Jacob, claims that it has been very challenging for clinics to use the service and also make it work for patients. In an interview, Jacob said to me:

Administratively, it’s really a nightmare. So, essentially, we’re gonna give you PrEP-AP, which is an entirely different coverage program in and of itself, and we’re gonna make it land into a clinic where you really have no infrastructure to deal with all of these different coverage plans. So, like, now we’re gonna give you a coverage plan where your providers can’t order everything that they want to. Where they can’t do everything that they want to do with a patient that they normally can do under every other insurance program. So now, you can only order these sets of labs [unlike ADAP, which allows providers to order many different kinds of tests]…with PrEP-AP you have someone come in and let’s say that they want PrEP, but they also have cluster headaches…you can’t touch any of those things, because it wouldn’t be covered under the program.
So, according to Jacob, the problem with PrEP-AP is that it acts as an incomplete insurance provider. While PrEP-AP is meant to facilitate access to PrEP, it not only demands new infrastructure from clinics, but limits their ability to work with patients. Although key Ending the Epidemic organizers regularly say that one of the overarching goals of the campaign is to get all New Yorkers into healthcare (ACT UP’s original call), a system that requires piecemeal approaches to cover new services clearly leaves important gaps in care where patients could easily get lost. Further, statistics on PrEP-AP use from the AIDS Institute indicate that the service is largely reaching the “usual suspects” in its early stages. Most users are men (96%) living in New York City (76%), and most (73%) have incomes over 100% of the federal poverty level. One statistic that is interesting, though, is that approximately an equal number of users are white (37%) and Latino (38%). Although the low use among African American (11%) and Asian (9%) men indicates that these groups still are being left behind, PrEP-AP looks like it may pose an opportunity to reach Latino men with healthcare (New York State Department of Health AIDS Institute 2016).

Provider Education & Mobilization

As described above, an increased focus on PrEP at the policy level results in programmatic changes at the provider level. One of the main challenges with mobilizing PrEP is alerting providers to PrEP’s availability and familiarizing them with its indications and uses. Thus, provider education is a key component of EtE. In 2014, the AIDS Institute awarded a major New York City hospital a large grant to conduct clinical education across the state around HIV and Hepatitis C. At the May 2015 NYers4PrEP Task Force meeting, Emily, who runs this program, reported that the program had conducted five half-day PrEP training conferences in Albany, Rochester, Syracuse, and Long Island, with an additional conference scheduled in the
Bronx in June. These conferences cover an explanation of PrEP and its uses, the CDC and New York State guidelines around using PrEP, as well as case-based implementation strategies and testimonies from a patient currently taking PrEP. As described above, Emily’s program also runs a toll-free line that providers can use to call in and ask a designated physician questions about PrEP.

As Stephanie noted during the May 2015 meeting, educating providers on PrEP is a “gargantuan task.” Emily acknowledged that this is true and that one of the challenges with providing education has been funding. Thus far, funding provided by the state for clinical education hasn’t specifically addressed PrEP, and so trainers have had to “carve out” funds from their existing grants to conduct educational activities. Another aspect of this “gargantuan task,” though, may be the providers themselves. Or, in the case of Ending the Epidemic, it may be the attitude that providers who focus on HIV have toward other types of physicians. During one of the EtE regional implementation described in Chapter 2, for example, Staten Island providers who participated in the borough’s Ending the Epidemic implementation meeting jokingly referred to their fellow medical providers as “unusual suspects” when it came to doing EtE work. Similarly, one of the participants in the October 2014 metrics meeting jokingly said, “If you’re gonna wait and train all the doctors [to roll out PrEP], it’s like waiting for Godot.” This quote may well be an indictment of slow-moving government processes just as much as a jab at doctors who are unmotivated to take such a training, but skepticism of general medical practitioners certainly pervades the Ending the Epidemic campaign. While EtE organizers regularly tout the importance of simply getting people into healthcare as a first step toward ending the epidemic, this dismissal of non-HIV providers suggests the opposite message by setting up general practitioners as an obstacle to adequate care.
Since Truvada can be used as HIV treatment in addition to preventing infection and PrEP is medication specifically meant for people who are not sick, mobilizing PrEP in a clinic setting can be especially tricky. In the most basic sense, where is PrEP “housed”? Most people I spoke with agree that everyone in the health system should have at least basic information about PrEP and know where to refer potential patients, since a request or indication for PrEP could show up in almost any healthcare setting. Programs like the NYC DOHMH’s PrEP detailing and Emily’s educational training take the first step in giving all different types of providers basic awareness around PrEP. However, the most important places for providers to know about PrEP are in STI clinics and primary care centers.

In many health centers, particularly now that private for-profit health systems are expanding, primary care centers and STI clinics may well exist within the same system, but staff don’t interact or share information regularly. Thus, as one provider in the Hudson Valley told me, when it comes to implementing PrEP at the provider level, “One hand has to talk to the other hand.” This particular provider has hosted internal educational lunches across their several sites, and also set up a protocol with another local provider that will refer patients to them for PrEP. Similarly, at one large hospital in the Bronx a team working on PrEP implementation has been examining how to move patients more efficiently through the system by decreasing “hand offs” so that patients don’t have to see too many providers. This can be particularly challenging when working with local NGOs that have to meet grants deliverables, which include seeing patients in their own offices before handing them off to the hospital. For patients, more visits to a medical provider can be prohibitive by requiring more co-pays and possibly more transport costs. The hospital has been exploring the option of conducting some required PrEP visits over the phone in
response to these challenges, but this practice might complicate reimbursement procedures from insurance companies.

On a higher level, one provider in Buffalo, Dan, pointed out to me that the current structure of provider reimbursement for primary care may push providers out of this field in general. During our interview, Dan told me that his clinic is starting to consider sharing patients with another major provider in Buffalo. When I asked why they would do this, he explained:

Medicaid reform. DSRIP all that…In a nutshell, I don’t wanna say this casually but basically, hospitals are getting out of the primary care business and so with the immunodeficiency clinic, they provide certainly HIV care, but they also do primary care for their patients. So, we’re looking at ways we can partner with [the other provider] to perhaps take their primary care patients and their immuno patients and, in turn, look at like cardiology and dermatology, all that going from our patients over to [the other provider].

According to Dan, providers are starting to lose money on primary care, which is why the potential partner clinic in Buffalo would be willing to hand over their primary care patients in exchange for specialty referrals. Dan’s clinic is able to take these primary care patients and still make money because they have an on-site pharmacy that generates revenue:

Financially, hospitals take a huge hit on primary care and we do as well. However, we have a pharmacy which…gives us revenue based on HIV-positive patients. So, transferring their HIV-positive patients for us is a win-win cuz they lose their money loser, which is primary care, but they gain all the specialty care that we refer back out to them…But on our end, we gain because the revenue’s generated through the pharmacy because they’re HIV-positive individuals…

In the case of Dan’s clinic, then, providing care to HIV-positive patients is actually profitable and could allow them to expand primary care services to HIV-negative patients as well. In a setting like Buffalo, where there are few HIV care providers, these providers already work closely together and shifting patients back and forth in this way may have little impact on the patients themselves. However, as the Bronx doctor pointed out, shifting patients among
providers and even within one health center in New York City could have negative consequences for patient retention.

**Case Study: The NYers4PrEP Task Force**

In a context where the very structure of the healthcare system almost forces providers to work together amongst themselves to achieve the Ending the Epidemic goals, collaborating and sharing information not only across provider sites, but across disciplines also is key. In this regard, perhaps one of the best examples of one hand talking to the other hand is the New Yorkers for PrEP (NYers4PrEP) Task Force. A truly inter-disciplinary space that emerged from conversations among providers, NYers4PrEP brings together service providers, researchers, government officials, and advocates on a monthly basis to discuss PrEP rollout across New York City. Stephanie was the original NYers4PrEP organizer, and in an interview she described how the task force started in 2012. Shortly after Truvada was approved as PrEP, Stephanie’s organization received a grant to host a PrEP conference. According to Stephanie, NYers4PrEP was born out of this conference because, “People just talked about the need to have a place to discuss PrEP and to talk about how it’s gonna be implemented on the ground in community…”

At the beginning, NYers4PrEP focused on advocacy around PrEP. As Stephanie told me, there was concern early on about how to create demand for PrEP and also how to create equal access “for all communities…people feared PrEP was gonna somehow highlight disparities and make worse disparities in healthcare.” More recently the focus has shifted to sharing information. Indeed, I attended a number of NYers4PrEP meetings between late 2014 and late 2015 (nine meetings in total), partially to conduct formal fieldwork and partially to stay informed on the state of PrEP in New York City. I found the meetings to be particularly informative, featuring presentations from state officials (e.g. the presentation on PrEP-AP described above), research
projects taking place across the city, and updates on global research, such as the results from several trials released at the Conference on Retroviruses and Opportunistic Infections.

Generally speaking, NYers4PrEP felt like one of the more inclusive spaces I encountered during fieldwork. While Stephanie was on the Ending the Epidemic Task Force and NYers4PrEP meetings often featured brief updates on the campaign, NYers4PrEP seemed to function in cooperation with, but separate from, the formal campaign. Unlike most of the recurring meetings related to EtE, NYers4PrEP attracted a rotating group of participants depending on the meeting’s topic. Over the course of a year regularly attending meetings, I encountered doctors and researchers from major hospitals and universities across the city, members of ACT UP, providers from major AIDS service organizations, a representative from Gilead, and representatives from state and city government. During the January 2015 meeting, attendees discussed who else they should reach out to for participation and the group suggested: young people (though apparently they had tried this before and one attendee said it had been difficult to get younger people to show up to meetings); transgender people; and several major medical centers across the city. I noticed representatives from some of the medical centers in later meetings, suggesting that the organizers may have done some outreach, but I never encountered a transgender person attending. At the February 2015 meeting, which featured a presentation on PrEP-AP, I arrived early to find several younger people seated around the outside of the room with most of the seats left open at the central meeting table. Sitting at the table, I made a joke to the room about being the only one at the table and one of the participants seated around the edge of the room said they didn’t want to take up space. While the metaphor of having a “seat at the table” comes up often in advocacy work to promote the participation of under-represented populations in key decision-making forums, here the young people in attendance literally declined this seat. This points to
one of the major barriers to participation that young people and other under-represented populations often face; already a powerless minority in a room, they often are too intimidated to exert power as seemingly simple as sitting at the table. During my interview with Emily, she made a similar point when discussing representation on the Ending the Epidemic Task Force:

So, I think the thing to think about is when you think about representation is don’t be like ‘Oh my god we have to have a transgender person’ and you walk down the street and you bump into one and you say, ‘Hey, you’re transgender. Let’s put you on the Task Force.’ I think it needs to be the right person…sometimes I just kinda wonder, were you filling in a demographic or were you really trying to find the right person?

While it is not clear that the younger people at the NYers4PrEP meeting had been invited in an attempt to include a particular demographic, it nonetheless bears noting that simply having young people in a meeting room doesn’t necessarily result in their meaningful participation.

Another moment when boundaries seemed to be defined within NYers4PrEP occurred during a meeting on PrEP research throughout the City. The main presentation focused on the “Tenaciously PrEPared” study jointly run by a major school of public health in New York City and a Harlem-based AIDS service provider. Some of the microbicide studies cited earlier in this chapter failed to adequately investigate possible barriers to adherence among young women recruited in sub-Saharan Africa, resulting in failed trials. In contrast, “Tenaciously PrEPared” began with a two-year ethnographic study among black MSM in Harlem to determine potential barriers and a trial was designed around the results of this preliminary study. In its implementation phase, “Tenaciously PrEPared” compares two interventions around PrEP adherence among black MSM in Harlem; one is a standard intervention that provides Truvada and condoms, and includes risk reduction counseling, adherence counseling, support groups, and quarterly HIV/STI testing. The “enhanced” intervention builds on the standard intervention with
a study support group, social networking and online support, SMS medication reminders, and peer navigators.

Since PrEP’s effectiveness has already been adequately proven, “Tenaciously PrEPared” is one of several studies currently being conducted in New York City that examine medication adherence. In addition, one community health center (which specializes in LGBTQ health) and a local public college are running a joint PrEP demonstration project that both evaluates a PrEP implementation program at the clinic and examines social and behavioral factors that might impact PrEP implementation programs and policies. Another medical center in the Bronx also is running a study that investigates the use of social media to facilitate PrEP uptake among young MSM of color. It is worth noting that all of these PrEP implementation studies run by some of the most influential research centers and healthcare providers in New York City focus on MSM of color.

Research demographics aside, the “Tenaciously PrEPared” presentation was most interesting for the dynamic that emerged in the meeting room during discussion. While this session was mostly attended by researchers, one activist from ACT UP was particularly vocal in questioning the study’s research methods, complaining that there is little “quality data” on PrEP. The presenting team from the school of public health clearly took offense to this statement and heated debate ensued as the activist offered his own perspective on barriers to PrEP uptake and adherence. Finally, a researcher from another institution tried to silence the activist by smugly asking him if the evidence he was using to support his claims was “anecdotal” or “scientific.” As explored in Chapter 3, by asking this question the researcher reinforced a power hierarchy between the activist and the other academics in the room. By suggesting that the “anecdotal” evidence that is often the purview of grassroots activists was less valuable than the “scientific”
evidence offered by the academics in attendance, she created a knowledge hierarchy that
specifically excluded the activist who might not himself have had access to scientific knowledge.
On another level, I found it personally disturbing, though perhaps not entirely surprising, that a
researcher in this field would intentionally denigrate an activist who may well be HIV-positive.
This is another way in which it can be difficult for under-represented populations to truly
participate in mobilizing PrEP as part of a broader Ending the Epidemic effort.

PART II: Mobilizing PrEP at the Patient Level in New York State

PrEP Opens Up Quality Care

Many of the main organizers involved in Ending the Epidemic agree that PrEP should be
a “gateway” to or a “tool” for quality healthcare, rather than an end game. In speaking about how
to measure success among patients who are on PrEP, Dr. Daskalakis outlined his vision for the
connection between PrEP and patient retention, but also pointed to one of the major challenges
that he and other providers face working with PrEP:

I’m gonna argue that PrEP adherence is a terrible quality [of care] indicator…Well, it’s a
great quality indicator for people who don’t prescribe PrEP or actually know anything
about it. I prescribe PrEP and I know that adherence means connection to care, because
people go on and off PrEP. And they should. So, using an HIV treatment gauge of “are
you taking your med every day?” is actually wrong…There is no viral load suppression
for PrEP. The end game is, are you still talking about this? Are you still in care? If PrEP
is the gateway to care, then care is the outcome. Not PrEP…I have 40 PrEP patients
myself…you know, they get into monogamous relationships. They stay on PrEP, they
maybe don’t. They get into a patch in their lives where they’re so busy they’re not having
a lot of sex…this is not for me, as long as I know that I can knock on your door and re-
start. And so they would look like a failure. They’re not a failure. They come every 3-6
months still…

According to Dr. Daskalakis, an ideal PrEP patient may go on and off the drug as their needs
change, but they continue to see their doctor on a regular basis. As he pointed out at a different
point in our interview, what is most important is that a doctor’s door is always open so that
patients feel they can engage or re-engage in care when they are ready.
However, as Dr. Daskalakis indicated in the quote above, PrEP presents a challenge to both providers and patients insofar as it is HIV treatment that also is used for prevention. For those providers who are used to an HIV model of care, strict medication adherence is important for maintaining efficacy (Paterson et al. 2000; Katzenstein 1997) and to ensure that patients don’t develop medication resistance (Havlir and Richman 1996). Thus, PrEP may prove challenging for providers by presenting an unfamiliar model of care. For patients, Dr. Daskalakis noted that those who do not strictly adhere to the medication may feel like a “failure.” In fact, recent research suggests that PrEP can be effective even if taken inconsistently or “on demand” (Spinner et al. 2016; Molina et al. 2015). However, during his tour of New York State conducting the Ending the Epidemic implementation meetings, Charles King often would cite a study currently under way which found that black MSM enrolled in the study were not able to reach the minimum level of adherence for the drug to be effective. Although some evidence of ARV adherence suggests that race is not in fact a good indicator of whether a patient is likely to have consistent adherence (Ferguson et al. 2002), there also is evidence that barriers to PrEP adherence differ among men of different racial backgrounds (Golub et al. 2013) and several adherence studies are currently under way to add to this evidence base. So, discussing PrEP and what it means to take the drug “successfully” may be challenging both for provider and patient, and providers need to navigate these discussions carefully in order to make patients feel comfortable.

Discussing sex and sexuality is one of the most important ways in which providers have to be particularly sensitive when working with potential PrEP patients. Taboos around talking about sex and sexuality in a medical setting come up often in Ending the Epidemic discussions, and this is another challenge to engaging patients in quality care. As Christina said to me during
our interview, “Doctors, they don’t really want to ask you about your sexual history.” Dr. Rivera made a similar comment, saying:

The challenge is that traditionally medical providers have been horrible about being able to have a great discussion about sexual history with a patient. So, you know…PrEP on some level requires providers to have a much more sophisticated discussion than they’ve been doing. So, before…there’s the ideal of how we talk to patients about sexual history, but…in terms of being able to provide care in a way where a medical provider can actually do something about people’s sexual health, most of it was really around testing for STDs and birth control, right? Because they could just say, ‘Well, you know, just make sure that you’re wearing condoms,’ because that was the only thing that was really available. And, ‘What form of birth control are you using?’ Those were sort of the two. And then, ‘I’m just gonna test you’ whatever the interval they thought was appropriate. But you didn’t have to get into a bigger, necessarily discussion around it…with PrEP you do have to get into a bigger discussion, because it’s about relative risks. It isn’t just, ‘You have a uterus and you’re having sex with someone who’s gonna get you pregnant. So, we have to have a discussion about birth control.’ There are a lot of different partner combinations and behaviors that can put people at risk for HIV and they’re often the sort of non-stereotypical, or…they’re not the combinations or relationships that most providers are comfortable talking about, which is monogamous heterosexual relationships…So, it has now required providers to have a much more sophisticated discussion that they didn’t have to have before in order to be able to deliver a certain type of care.

Echoing her almost exactly, Dr. Daskalakis said:

You have to be honest and I feel like this is one of the things, it’s one of our challenges probably state-wide. You have to have a conversation that acknowledges that it’s ok to tell me that you’re at risk. And that’s not easy…you go to the doctor and, we’ve all been there, ‘You don’t drink, right? You don’t smoke, right?’...And so the assumption is that you’re gonna say ‘Yes yes yes yes yes, I am your golden child.’ PrEP has opened a door a bit where you’re actually able to say ‘Look, we have something for you if you don’t use condoms all the time. Do you use condoms all the time?’ ‘Well, maybe…’ ‘No. Really tell me’…do they all say yes to PrEP? No, but then…you know what their risk is and you know what else you can do for them…Because before all you could say was ‘You better use condoms all the time.’ ‘No, I don’t do it.’ ‘Ok, well, you better use condoms all the time.’ It’s a very useful tool.

For both of these providers, then, PrEP offers both a challenge and an opportunity through the kinds of conversations it can open up between providers and their patients. As Christina noted, many providers are uncomfortable talking with patients about sexuality, and as Dr. Rivera said, PrEP may provoke particularly sensitive conversations about non-traditional sexual practices.
However, Dr. Rivera and Dr. Daskalakis agree that PrEP can be a useful “tool” for helping providers to better assess their patients’ lives and needs when providers are able to have these sensitive conversations.

For those providers who have these conversations in the right way, they may be helping to advance the Ending the Epidemic goal of using PrEP as a way to get more people into general healthcare. As Dr. Daskalakis said to me:

… right now it’s hot and when there’s something in healthcare that people want, they tend to pursue healthcare. If there’s nothing that they want, they’re not gonna come see you. So, it’s our shot at making PrEP look exciting and sexy to say that this is a part of care…What number of young MSM do I see now who never would have seen me? So many. So many who would never have gone to the doctor…So, it’s like a game-changer for care.

However, connecting people to healthcare and retaining them in this system are different things. We know that patients are more likely to meaningfully engaged in care and stay there if they feel informed and cared for (Irvine et al. 2014; Bertakis 1977). So, if as Dr. Daskalakis and Dr. Rivera suggest, PrEP can be a useful tool to opening up deeper conversations with patients that make them feel more comfortable in a healthcare setting, then it may also be a tool for retaining patients in care as well.

*PrEP is a Marketable Product*

Dr. Daskalakis’s statement above points to another running theme in the Ending the Epidemic campaign, which is that PrEP is a marketable product. As Emily said in our interview, when Truvada was first approved as PrEP many people were hesitant to use or endorse it because they were thinking, “What if this is a ploy by Gilead?” Emphasizing this mistrust of the pharmaceutical establishment, Emily wryly commented, “Everything is a ploy by Gilead.” However, this mistrust has given way over time so that Emily says, “Now it’s completely swung to the other side. That’s all I hear. PrEP PrEP PrEP PrEP PrEP PrEP PrEP. Everybody wants PrEP
trainings.” As this shift has occurred, PrEP users, providers, and government institutions have themselves become willing and reliable PrEP marketers.

Indeed, Ending the Epidemic already is structured around the idea that patients are “consumers” of healthcare services, which puts them in a prime position to receive marketing messages. For its part, Gilead seems to focus its marketing efforts on service providers by hosting informational dinners and providing funding for educational events or campaigns like “Swallow This” (below).23 However, EtE organizers and providers themselves have picked up on the idea that PrEP needs to be marketed to potential patients. As early as the October 2014 metrics meeting, one attendee suggested “selling” PrEP to potential patients through those who are already using it, while a participant at the May 2015 NYers4PrEP meeting said that “We can create demand” for PrEP. Further, one of the presenters at the October 2015 Ending the Epidemic implementation meeting in Queens noted that New York City had been engaging in “Direct-to-consumer PrEP work,” drawing a parallel to direct-to-consumer advertising. This advertising has played out in online ads for PrEP that the NYC Department of Health and Mental Hygiene (DOHMH) and also the Monroe County Department of Health have placed on hookup apps directed to MSM, like Grindr, as well as subway and bus stop posters throughout New York City that have been sponsored by DOHMH and various AIDS service organizations (more on these below).

In fact, these approaches seem to be very effective. As Demetre Daskalakis noted during our interview, there has been an “explosive” increase in PrEP awareness in the past couple of years as reflected in the City’s annual Sexual Health Survey (Mensah et al. 2015). Recognizing

23 Note that I attempted to interview the Gilead representative to the Ending the Epidemic Task Force, but the company would not allow him to speak with me. Although he then put me in touch with a contact in Gilead’s marketing department, I was never able to get a response despite multiple follow-up attempts.
the influence of ads run by both New York City and by the state, Dr. Daskalakis said, “My favorite and my most important [survey response] is ‘my friend told me.’ When someone starts PrEP they become a recruiter. It’s actually amazing. I have one man…who’s now sent me 10 people.” Similarly, Dr. Silva told me that she often discusses PrEP with her younger patients and, even if PrEP is not for them, “I tell them, ‘You need to tell your people about this stuff.’”

Enthusiastic PrEP users also are recruited by government agencies and AIDS service organizations to serve as spokespeople and market PrEP to both providers and peers. Following a long trend in using “testimonials” as a way to draw people into AIDS activism (Nguyen 2002), these presentations often involve PrEP users describing their own experience with PrEP and answering questions from the audience to both promote and demystify the drug. One such event, sponsored by one of New York City’s community health centers, will be examined in detail in Chapter 5.

“Swallow This”

One particular NYers4PrEP project, the “Swallow This” campaign, illustrates one of the most striking aspects of PrEP mobilization in the context of Ending the Epidemic; PrEP is a marketable product. Funded by a grant from Gilead, NYers4PrEP’s “Swallow This” was a direct-to-consumer marketing campaign that was meant to respond to what Stephanie characterized as a swath of early PrEP adopters among white, gay, middle-income men. In contrast, she observed a dearth of information around PrEP in communities of color. During our interview, I prompted Stephanie on an earlier point she made that providers were concerned PrEP would highlight pre-existing disparities in healthcare; did she see this notion of “haves” versus “have nots” playing out on the ground? Pointing to the importance of access to information in healthcare, Stephanie responded, “I think it’s played out a little bit. Not ‘haves’
and ‘have nots.’ It’s ‘know’ and ‘know not.’” As such, the “Swallow This” campaign was designed to be educational with a “bit of a push” towards getting more information. Since it was “branded” with Harlem United, the name of a prominent AIDS healthcare organization in Harlem, the implication was that more information could be found on the organization’s website. According to Stephanie, the campaign was “very tailored” to Harlem and Washington Heights with a target audience of HIV-negative black and Latino MSM. In line with this goal, Harlem United hired a social marketing agency that is known for marketing HIV treatment to MSM of color to develop the campaign.

According to Stephanie, “Swallow This” was meant to be “Edgy and provocative, but fun…and it doesn’t sort of ram PrEP down your throat. It’s like, ‘Is PrEP for you? Maybe it is. Check it out.’” Launched at New York City’s Gay Pride events in June 2015, the ads were placed on promotional materials distributed at Pride, bus stops throughout Harlem and Washington Heights, and online as well.

**Figure 2. A “Swallow This” campaign poster**

![Swallow This poster](source: Harlem United. Retrieved from www.harlemunited.org/swallow-this-launch/)

The ads feature a close-up of a man’s mouth (two different versions of the ad show one man with light brown skin and another man with darker skin) with his tongue sticking out, presumably
about to swallow a distinctive blue Truvada pill. The ad therefore offers a double entendre: at once it suggests that men of color should be swallowing PrEP, but at the same time “swallow this” implies a blowjob. In addition to being “dramatic” and “visually striking” as envisioned by the advertising company, clearly the ad also is “provocative” as Stephanie wanted it to be while explicitly targeting MSM of color.

Another noteworthy aspect of “Swallow This” is its focus on PrEP alone and not in combination with more established prevention options, such as condoms. In fact, the CDC (http://www.cdc.gov/hiv/basics/prep.html) and the WHO (http://www.who.int/hiv/pub/guidelines/qa-prep-msm/en/) suggest that PrEP should always be used with condoms to prevent other STIs, and the focus groups used to design “Swallow This” also expressed a preference for condoms. As Keith, a member of the advertising team that designed the campaign pointed out, condoms have been “the party line” for a long time and he didn’t get the sense from the focus groups that participants were “clamoring to ditch the condoms.” Rather, participants seemed to view PrEP as an additional safeguard as opposed to an alternative to condoms. As such, Keith suggested that it is going to take time for men who have been using condoms to transition into a “new world” where PrEP is an alternative. In contrast to the “Swallow This” focus group, one PrEP user I interviewed, David, told me he thinks people don’t want to use condoms anymore. As a white man who identifies as gay, Jake had used condoms for the first 30 years of his life until he entered into a long term relationship. After this relationship ended, Jake started taking PrEP precisely because he didn’t want to return to using condoms as he had been doing for decades before.

Differing attitudes toward condoms between generations and among different populations was certainly a running theme through my research. For people who are older, and especially gay
men who experienced the early days of the AIDS crisis, condoms have long been considered the only effective method of HIV prevention on offer. Thus, these men may be especially resistant to “ditching the condoms” that have kept them safe for most of their lives. Further, Keith noted that the “Swallow This” focus group participants seemed particularly conservative in their views toward sex, and showed a “heightened sensitivity” toward stigma. He suggested this sensitivity could have to do with participants’ identification as young men of color, and with their awareness of homophobia and lack of community support in neighborhoods like Harlem and the Bronx. This awareness could make the focus group participants especially sensitive to stereotypes of gay men as overly promiscuous. Popular discourse around PrEP certainly has highlighted this stereotype, most notably through the prevailing concern that, without the threat of HIV to curtail them, gay men on PrEP could become “Truvada whores” having indiscriminate sex all over town (Calabrese and Underhill 2015). So, the enthusiasm for condoms expressed in the focus group may reflect participants’ desires to distance themselves from this stereotype in an unwelcoming setting. Or (or, in addition), participants might have been hesitant to express real interest in condom-less sex in a setting where they might be judged by their peers as well as by the group facilitator. It is noteworthy, then, that even after the group expressed this concern the final “Swallow This” campaign does not mention condoms.

In this respect, “Swallow This” differs somewhat with other public education campaigns for PrEP, such as the New York City Department of Health and Mental Hygiene’s “Play Sure” campaign. “Play Sure” posters featured prominently on New York City subways and typically showed different types of couples (sometimes homosexual, sometimes heterosexual, and sometimes with one partner of ambiguous gender orientation) with the line “We Play Sure” over different combined options for HIV prevention, such as “PrEP + HIV Treatment + Condoms”
(www.on.nyc.gov/playsure). Similar to “Swallow This,” “Play Sure” takes an approach to HIV prevention that sends a lighthearted message; sex is not something to be ashamed of and HIV prevention can be part of a normal, enjoyable sex life. Jake told me he likes these kinds of ads precisely because they send an “empowering” message around sex and PrEP use. Like “Swallow This,” “Play Sure” also focuses largely on people of color. Unlike “Swallow This,” though, the City’s campaign offers a broader perspective on PrEP both as part of a range of prevention options, and as a method appropriate for New Yorkers with a range of sexual and gender identities.

Still, the “Swallow This” marketing approach seems to resonate, and especially its underlying focus on race and sexuality. Stephanie told me in our interview that she has had several conversations recently with people who wanted to use the ads for their own purposes. As she described it, someone called her from Miami to inquire about using the images: “he’s not part of an organization, he’s just a guy. He’s on PrEP. And he wants to get the word out.” Someone also came up to her at the US Conference on AIDS and said he had taken the image for his own website, so “it’s already gone viral.” Recently, a man appeared in Stephanie’s office asking for 22 “Swallow This” posters, although he wouldn’t say where he was from or what exactly he wanted them for. Stephanie brought out some materials, but the posters with the darker-skinned model were all gone and the visitor didn’t want the “lighter-skinned dude.” As this incident illustrates race, and particularly racial specificity, may be a particularly relevant factor in making “Swallow This” successful. However, an ad directed at MSM in a neighborhood that is predominantly composed of people of color can be a tricky proposition. As Stephanie pointed out during a NYers4PrEP meeting, a prominent church in Harlem has become known for
advertising homophobic messages on its marquee. So, “[homophobia] is real. And it’s relevant. And it’s right in Harlem.”

Christina, the youth health educator introduced in Chapter 2, agrees with Stephanie that homophobia is a serious problem in Harlem and suggested that “Swallow This” might not be effective for this very reason. When I mentioned the campaign to her during our interview, Christina said, “Yeah, there’s some in my neighborhood. And that’s the thing. My neighborhood, Washington Heights, if you put a gay ad, no one’s gonna want that pill…They’re doing it well by putting it in minority communities, but it’s not the right advertising.” Indeed, one participant at a NYers4PrEP meeting suggested that the group should attempt to “normalize [PrEP] as much as possible” so that discussing PrEP becomes as normal as discussing real estate in New York City. Further, normalizing PrEP would mean that potential patients would request PrEP from their doctors in the same way they might request birth control or Viagra. These comments obviously miss the point that many of the people targeted by PrEP campaigns are not wealthy enough to have regular discussions about New York City real estate. In addition, it ignores the climate around sexuality in neighborhoods like Harlem and Washington Heights that might preclude a drug associated with male homosexuality from becoming “normal.” Under these circumstances, the best way to make PrEP seem normal might be to reach out to a broad audience, rather than targeting MSM so clearly. As Christina suggested, advertising should make it clear that PrEP is pertinent to many people, not just MSM: “I know they’re really big on young MSM…I don’t think that they’re focusing too much on trans. Also women are being left out, especially in the PrEP and PEP. Even though I know it’s lower in women, they should still be educated about it.”
Further, if reaching young people is a priority, then print advertising and even online ads may not be the best way to do this. On the one hand, ads placed on sites like Grindr have a clear intended audience and are unlikely to reach people other than MSM. As Christina said, “I just feel like the media is a huge deal…that’s where most younger people spend most of their time…Instead of hearing it from word of mouth they see it online…” For example, she described a text messaging program her organization recently started that allows young people to send sexual health questions via text and then receive messages back with information on nearby clinics and testing services. Christina felt this program worked well, because “We got a lot of [Facebook] ‘likes’ on that and it’s because it’s a text message. It’s so quick…and adolescent attention span is just so small now.” Similarly Jacob, a PrEP provider mentioned earlier in the chapter, suggested that accessing information on PrEP can be challenging even for those who are motivated:

Jacob: So, it’s like, we want people to be doing PrEP. We want people to be doing PrEP-AP, but we’re also gonna make it really weird and alienating for you to find this information. So then you have to call someplace, which we know the demographic that we really want to get on this, they’re not like, ‘oh, I’m gonna call this number.’
Interviewer: They don’t call anyone.
Jacob: No. Exactly. They’re like ‘I wanna pull it up on my phone. I want an app. I want you to just basically connect the dots for me…And make it so that even I can schedule my first appointment through this app…’

Both Christina and Jacob agree that reaching young people with messaging around PrEP and even facilitating their access to the medication requires a level of media savvy and technological sophistication that certainly organizations like the AIDS Institute, and even most providers, don’t have.

Discussion & Conclusions: Who Should Be PrEPared & How?

As I have discussed through much of this dissertation MSM of color, and particularly young MSM of color, are the group to which Ending the Epidemic directs most of its efforts.
This is partially because the campaign claims to respond to statistics showing declines in new infections among all other populations, which ostensibly makes this group desirable potential PrEP consumers. Further, this chapter shows that when it comes to PrEP in particular, the field of HIV prevention at this point has already mobilized around this population. PrEP efficacy studies have been concentrated around MSM since Truvada was first discovered to prevent HIV as well as treat it, and when women or transgender populations have been included in these studies they either have constituted a small minority (e.g. trans women in the iPrex study), or the study has failed due to its design. As such, the evidence base around PrEP for MSM continues to grow and studies on adherence that have been running in New York City since before the EtE campaign launch also show a particular affinity for MSM of color.

In its official documentation, the Ending the Epidemic campaign follows this lead by paying particular attention to MSM of color in the Blueprint section on PrEP (as well as in several other areas of the document) and some efforts related to EtE, such as the “Swallow This” campaign, have been targeted to this population as well. Certainly, some of this work has gained traction. For example, Stephanie noted that “Swallow This” had “gone viral” and she had received several requests for marketing materials to distribute both within and outside of New York State. In this case, the specificity of the ads seemed to make them particularly resonant. However, both Stephanie and Christina noted the potential consequences of running a sexually provocative campaign for PrEP in a neighborhood where residents often are not tolerant of homosexuality.

In this context, it bears thinking about PrEP not solely as a pill that can be marketed, but as an entire health intervention. While some of the anthropological literature (e.g. Biehl 2009), points to drugs replacing public health interventions in worst-case scenarios, the current medical
protocol around PrEP requires that patients regularly access healthcare to remain on the drug, and Ending the Epidemic clearly has put mechanisms like PrEP-AP in place to facilitate patient access both to the drug and to care. However, as Petryna and Kleinman (2006) point out, pharmaceuticals (or really any marketable consumer product) do not fall on equal social ground. In this early phase, PrEP-AP is still unlikely to reach women, the poor, and black men, particularly those living outside of New York City. This may be due in part to the current structure of the health system in New York State (and indeed, beyond), which financially rewards providers for offering specialty services over general primary care and encourages a piecemeal approach to healthcare. It may also be due to the fact that, as Charles King told me in our interview, historically it has been difficult to bring people of color “around to care…I think we see that with PrEP uptake right now.”

Further, Ending the Epidemic efforts around PrEP seem to align with the apolitical “activism of awareness” that Gottlieb (2013) found among HPV vaccine advocates. While some initially expressed concern that PrEP rollout was just a “ploy” on behalf of Gilead, other than some skepticism around Gilead’s role on the EtE Task Force, this skepticism seems to have largely given way to concern with spreading the word about PrEP as far and as wide as possible. In this case, as Stephanie noted, the goal was to reach the “know nots” with information about PrEP in order to encourage them to seek out further information. As suggested by Charles King’s claim that the official Ending the Epidemic campaign had to be preceded by working with drug companies to negotiate prices, EtE clearly functions in partnership with companies like Gilead, and particularly when providing PrEP. And it is worth noting that it may be especially worth it for pharmaceutical companies to heavily promote preventative drugs in particular. As Dumit (2012) points out, the future of the pharmaceutical industry lies not in treating the sick, but in
treating the healthy. In this respect, EtE participants are almost doing Gilead’s work for it.

However, it should be noted that the demand to include PrEP as a significant piece of Ending the Epidemic came from the “community,” as Stephanie and Mark Harrington noted, and was not necessarily prompted by drug company interests.

As medical providers like Demetre Daskalakis and Dr. Rivera would agree, one of the best ways to “market” PrEP is actually by word of mouth. The ultimate goal for both of these providers, and indeed for Ending the Epidemic in general, is to get more people into healthcare by seeking out PrEP. Once in care, discussions about PrEP can be a “tool” for providers to have better discussions with patients about their overall health.

Based in Brooklyn, Dr. Rivera’s current patient population doesn’t look like the official EtE picture of a PrEP candidate. Rather, she told me, “because I work in a Caribbean population, most of their HIV transmission, there’s more HIV transmission in the heterosexual population than in the MSM population compared to other ethnic groups.” For this reason, Dr. Rivera suggested that her discussions with patients about PrEP are challenging because “then you’re asking someone who knows that they’re in an unhealthy relationship and who knows that they’re staying even though it’s not good for them. You’re asking them to take a pill every day to remind them of exactly that fact.” Since “heterosexual” HIV transmission often is a code word for transmission from a man to a woman, Dr. Rivera seems to be talking about Caribbean women being at high risk for HIV in this case, and indeed she acknowledged during our interview that “particularly women of color, that’s the other population that’s at high risk for HIV just proportionally.” In her previous job working at a clinic in Manhattan, Dr. Rivera said she specifically sought out young women of color and transgender men as target populations for PrEP. Indeed, several AIDS service organizations jointly sponsored a PrEP rally for women that
ended up being scheduled the day of the first Ending the Epidemic Task Force meeting, which
further speaks to the need to reach other populations in addition to MSM of color with messaging
around PrEP. These populations, too, are the “know nots.”

In this sense, then, using PrEP as a “tool” to open discussion, rather than a marketable
product with a particular consumer population may be the most effective approach to mobilizing
the drug across a range of patient identities. As Dr. Rivera said, when she has sensitive
conversations with her patients about issues that range from homelessness to sexuality to
emotional intimacy between partners, this “makes it easier for me to have a discussion with them
that doesn’t feel shaming.” This in turn encourages patients to share their real health concerns
regardless of age, race, gender, or class, making them more likely to meaningfully engage in
healthcare and to realize Ending the Epidemic’s biggest goal.
“We have become conditioned to treat people according to our own beliefs when we should be looking at behaviors.”
- William, transgender activist

Following the previous chapter’s focus on how PrEP is mobilized in the Ending the Epidemic campaign, this chapter examines the gendered, sexualized, and racialized aspects of EtE’s heavy PrEP promotion. Since early studies proving oral PrEP’s efficacy focused primarily on men who have sex with men (MSM), the gender and sexuality implications of PrEP have been clear from the beginning. With new HIV infections concentrated largely among MSM, particularly MSM of color, in New York State (New York State Department of Health AIDS Institute 2012), Ending the Epidemic has placed a particular emphasis on targeting PrEP to this population. The paradox here is that much of the EtE rhetoric aims to affirm the racialized and gendered sexualities of MSM of color while at the same time singling them out as a public health threat. In some respects, the threat of black male sexuality is nothing new, as it harkens back to myths of the black/brown rapist prevalent across the globe under colonialism and under U.S. slavery (e.g. Spivak 1988). However, parallels that are regularly drawn between oral contraceptives and PrEP during EtE meetings bring to mind attempts to medicalize, and therefore control, (women’s) sexuality using pharmaceuticals (Watkins 2001). They also raise comparisons to Colen’s (1995) theory of “stratified reproduction,” suggesting differential access to HIV prevention across lines of race and class. If mobilizing PrEP is both about who is “at risk” of contracting HIV, and who is “risky” and might pass the virus on, what is the interplay between risk, gender, race, and sexuality in this case? What does this say about the kinds of
gendered and racialized identities that ultimately are condoned by the campaign, in turn gaining meaningful access to PrEP?

**Gendering PrEP Promotion**

*Focus on MSM of Color*

Given the strong emphasis on MSM, and particularly young MSM, of color throughout the Ending the Epidemic campaign, one might wonder if such an emphasis is justified in the case of PrEP as well. In fact, the statistics do show that HIV incidence (new infections) has remained stable among MSM from 2010 - 2014, by far the largest proportion of people newly diagnosed with HIV in the state, while it has steadily fallen among other sub-populations grouped by transmission risk (e.g. sharp declines among people who use injection drugs). Further, the ratio of new diagnoses among men versus women rose from 3.2 in 2010 to 3.8 in 2014, and while new diagnoses among black, non-Hispanic populations declined generally during this period, there was a slight uptick in new diagnoses from 2013 -2014 (also seen in whites, though in smaller numbers). However, there also were overall declines in new diagnoses among younger populations (e.g. 20-24 and 25-29), although older age groups realized much larger decreases (New York State Department of Health AIDS Institute 2016: 40-42).

In presentations and meetings related to “Ending the Epidemic,” Department of Health staff and campaign organizers often would show line graphs that depict these differentiations in HIV incidence among populations in New York State to justify an intense focus on young MSM of color for outreach efforts, including PrEP marketing. Certainly, this trend is worrisome. It means that these men are not getting the messaging, social support, and healthcare to protect themselves from HIV infection. So, in an effort to address this disparity, much PrEP messaging has been directed to young MSM of color in order to encourage them to practice safer sex. As
outlined in Chapter 4, for example, the two versions of Harlem United’s “Swallow This” PrEP marketing campaign depict a man’s open mouth with his tongue extended and a blue pill (Truvada) on it behind the caption “Swallow This: This pill is changing HIV prevention.” In both cases, the man appears to be black or Latino, and between the caption and the man’s extended tongue, the underlying message is that PrEP is related to sexuality and sexual behavior.  

Who Is Left Out  

However, as I pointed out in Chapter 3, statistics can tell many different stories depending on which numbers are presented and in what configuration. Further, we know that research on HIV/AIDS is predisposed to always placing MSM at the top of the risk hierarchy (Glick Schiller et al. 1994). During a discussion of “key populations” at the December 15, 2014 meeting of the EtE Task Force Prevention sub-committee, for example, one of the co-leaders of the group that was appointed specifically to develop a list of key populations cited a controversial statistic. Dr. Diaz noted that the key populations committee “asked for statistics and we got statistics,” and while it wouldn’t be “popular” among the group, statistically white men are still a large percentage of the total population of MSM living with HIV. Interestingly enough, this comment provoked relatively little conversation, other than some discussion of the relationship between this statistic and geography; outside of New York City, MSM living with HIV are more likely to be white than are men living in the city (New York State Department of Health AIDS Institute 2016: 21-24). Though, as one sub-committee member pointed out, “But if you want to end the epidemic,” it is more important to focus on potential new infections rather than on people who already are infected. In other words, if ending the epidemic is really the goal of the campaign, then preventing new infections is the most effective way to do this.
Despite the point made above that prevention is most critical to ending the epidemic, it is interesting here that white men were quickly dismissed as a potentially important population for Ending the Epidemic to address. Indeed, while white men may make up a smaller proportion of new infections, those who already have HIV could potentially pass the virus on to their sexual partners if they are not on medication and virally suppressed. And there is nothing to say that white men don’t have sex with men of color, and vice versa. That said, white MSM are more likely to adhere to HIV treatment medications than are their counterparts of color (Schackman 2007; Mehta et al. 1997), which might translate to PrEP adherence as well. Treatment adherence also correlates to a higher rate of viral suppression (Gifford et al. 2000). So, when promoting PrEP among MSM, it may make sense to focus on MSM of color for these reasons.

However, there are other examples of populations that might especially benefit from targeted PrEP promotion, but which tend to receive less attention in formal presentations and outreach efforts. For example, at the May 2015 meeting of the AIDS Advisory Committee’s Ending the Epidemic sub-committee, Demetre Daskalakis claimed that new HIV diagnoses are a “story of disparity” and “If you focus specifically on women, the disparity is even greater.” Since EtE organizers often point to the statistics around new HIV diagnoses among young MSM of color as supporting evidence for the campaign’s focus on this population, notable disparities in new diagnoses within another population should provoke some discussion. However, this comment was made almost in passing and Dr. Daskalakis’s PowerPoint presentation didn’t include any slides that addressed gender disparities in new diagnoses.

This moment brings to mind an interaction I had with Gina, who I met at HIV/AIDS Legislative Awareness Day in March 2015. As an HIV-positive resident of Westchester and a public advocate for HIV awareness, Gina had been assigned to our lobbying group to speak with
representatives from her district and to promote some of the policies laid out in The Blueprint. While waiting on a long line to enter the state capital building, I asked Gina about her experience as a woman in the field. Gina told me the story of one experience she had speaking publicly at an event where the word “women” was never mentioned. In fact, Gina’s voice is hoarse as a result of radiation for laryngeal cancer, and she was under the impression the crowd thought that she was transgender. Indeed, HIV researchers and advocates have been increasingly paying attention to the virus among transgender people, and particularly transgender women. So, it makes sense that an audience at this kind of event would expect a transgender speaker, albeit alarming that Gina’s identification as an HIV-positive woman of color may have gone unnoticed.


Similar to the statistics on HIV prevalence in white men that prompted little discussion at the December 2014 Task Force meeting, the examples above suggest a certain tendency to overlook (cisgender) women as relevant to the campaign. This means that, in turn, women also receive less attention when it comes to PrEP. Having already interviewed Emily, the director of an HIV/AIDS educational training program at a major New York City hospital, in 2015, I approached her for a second interview in late 2016 to discuss her work on women and PrEP. As Emily said to me, “Women are left out of the PrEP conversation constantly.” She went on:

Two weeks ago, I was at the HIV prevention research conference in Chicago and every time PrEP came up it was always framed as a gay man’s case, gay men, MSM…Nobody ever brought up PrEP in women and it was just so frustrating…It’s 2016, the FDA approved Truvada for PrEP in July of 2012 and we’re still not talking about women as much as we should.

In fact, during our interview Emily described attending one of a series of PrEP “rallies” at Gay Men’s Health Crisis (GMHC) in 2014, where:

…I was like one of very few women in the audience. And I went up to him [Demetre Daskalakis, one of the event’s organizers] afterwards and I said, “You know, we really
need to do something for women.” And I was like “PrEP, you know, has a very kind of male gay-centric kind of focus and, you know, women need user-controlled prevention methods.” Sort of like, I don’t know, in the ‘60s when we needed birth control.

In response, Emily organized her own event as part of the GMHC series titled, “PrEP Rally 4: What Does PrEP Mean for Women?” in New York City in October 2014. Echoing Emily’s feeling that the PrEP conversation is largely focused on/among gay men and MSM, one of the women participating in the event’s PrEP user panel said, “It is very different being a female in the PrEP program…It would be great to have more support for women, there’s not a lot out there…” Another panelist noted:

> When I found out that such a thing as PrEP existed, which I only found out this summer…Of my female friends, only one person had heard that there was a drug that could prevent HIV. All my gay male friends knew about it…and of my straight male friends, only one knew that this existed…and my friends are for the most part a well-educated and sex-positive bunch. So, if they didn’t know this…does anybody know?

In this context it is particularly ironic, then, that the inaugural meeting of the Ending the Epidemic Task Force, which was announced mere days in advance and which Emily was invited to attend, was scheduled for the same day as the rally. As Emily put it, “I was like, ‘Really, did you have to schedule it on the same day of the PrEP rally that I’ve literally been working on for six months?’” Although Emily ultimately was able to attend both events, she had to leave the Task Force meeting early in order to catch a train back to New York City to host her own event.

The rally was co-sponsored by a group of prominent NYC-based AIDS advocacy organizations, such as ACT UP and GMHC, along with the hospital where Emily works, and she described it as an event “for women by women.” Interestingly enough, the co-organizers’ definition of “women” was very broad in this case. As Emily told to me, a flyer that went out to promote the event featured the following description:

> “A community discussion on HIV, pre-exposure prophylaxis and women.” And then we put an asterisk by the word “women” and said, “We invite women in all of our diversity,
including gender identity and sexual expression to attend.” Because we didn’t want people to think, particularly transgender women, to think that they couldn’t attend…

So, the organizers made a clear effort in this case to include transgender women in the rally, which featured a presentation on the science behind PrEP and women, a short policy presentation, and testimonials from three women who use PrEP. Indeed, one of the panelists remarked “…it’s great to be part of an all women panel talking about HIV,” acknowledging that a panel made up entirely of women is rare in the field. However, it is worth noting that none of the panelists themselves appeared to be transgender. Two of the PrEP users who spoke identified as heterosexual and one as bisexual.

Still, diversity was a key theme in the rally as addressed by Stephanie (also a member of the Ending the Epidemic Task Force). Stephanie delivered a short presentation on the policy implications of PrEP for women, telling the audience it was “fitting” to hold an event focused entirely on women and PrEP. In fact:

Not only is it fitting, it’s essential…In 2012, black women accounted for the majority of new HIV diagnoses in females here in New York City. That’s about 64%. The death rate among people with HIV and AIDS was higher in females than it is in males that same year. And among transgender women, male to female, about 92% of newly diagnosed [from 2008 – 2012] were black and Hispanic…The disparities between black and brown women and white women, and infection rates, still remains alarming. So, basically, we can’t afford to dismiss any new prevention intervention if it’s safe and effective…Truvada as PrEP is one such intervention.

Stephanie went on to show a PowerPoint presentation, which featured a slide that read, “PrEP is not for EVERY woman, but it’s an option for ALL women; PrEP works for women who take it; Black and Brown Women; PrEP is for us, too!” As Stephanie went on, she said, “As an African-American woman, I hope it’s ok that I address this to you. But..I’m really concerned about communities of color and PrEP…I want my sisters of color, black and Latina women, for us to know that PrEP can be for us, too.” Due to high rates of infection among women of color,
Stephanie claimed, there is “an ethical imperative” to make new HIV prevention options available in an “equitable manner” for women of color. “If we don’t, we risk creating a system of ‘haves’ and ‘have nots’…”[and] Our reality tells us that we need to work hard…” to make women of color aware of PrEP and to make PrEP accessible. Here, Stephanie specifically pointed to the importance of targeting women of color with messaging around PrEP given the “alarming” statistics around disparities in infection rates and in deaths. Further, she included transgender women in her presentation, citing a statistic that brings health disparities specifically among transgender women of color into stark contrast with their white peers.

Stephanie’s presentation also included the key message that PrEP is not meant for everyone, but it is an option for everyone. So, while Stephanie pointed out that women of color need to be targeted more with messaging and knowledge around PrEP, she wasn’t suggesting that healthcare providers simply dole out the medication right and left. As she joked:

I’m a PrEP enthusiast and…people get really worked up about PrEP as if we’re gonna start dispensing it to everyone. And I say it’s probably not gonna end up like condoms, we’re not gonna find in the lobbies of community-based organizations, bowls of PrEP [laughter]. It’s for people who need it, right?

So, Stephanie emphasized her point that certain populations may need greater attention when it comes to PrEP, but ultimately it is a prescription based on individual need and choice, not on a particular demographic profile. This message of prioritizing behavior over identity is one that scholars have put forth themselves (González 2007) and it is similar to the message that the EtE Task Force’s Key Populations sub-committee tried to convey when presenting their work identifying specific populations to target with campaign-related programming. Addressing the full Task Force in November 2014 one of the sub-committee’s co-leaders said, “We are identifying them as populations,” but the message the group was trying to convey was that “it is not who they are,” but behaviors that put people at risk. He went on, “We don’t want to
stigmatize in the context of trying to de-stigmatize.” So, this also is a message that the EtE Task Force made some attempt to convey, although the final Blueprint does point to specific populations that should receive special attention in PrEP marketing campaigns.

As described in Chapter 4, the New York City Department of Health and Mental Hygiene made some headway in this regard with the “Play Sure” HIV prevention campaign they ran in conjunction with Ending the Epidemic. “Play Sure” was aimed at multiple identities along the lines of race, gender, and sexuality and the campaign promoted PrEP as only one part of several types of prevention regimens (e.g. PrEP + condoms or TasP + PrEP). Models in “Play Sure” posters portrayed a variety of racial/ethnic identities and sexualities as well as gender identities, although this isn’t made explicit in the campaign posters.

Figure 3. An image from the “Play Sure” campaign

Source: New York City Department of Mental Health and Hygiene. Retrieved from http://cunyhart.org/implementationscience/
In the words of Demetre Daskalakis, one goal of “Play Sure” was to portray the people in the campaign such that viewers could not tell whose “gender is what, race is what.” The campaign launched at World AIDS Day 2015 at the Apollo Theater in Harlem, where Carmen Carrera, a former contestant on “RuPaul’s Drag Race” and advocate for HIV awareness in transgender communities, walked onto the stage and posed for photos wearing a Keith Haring-print dress designed especially for the event. Carrera’s presence and her attire made the event feel slightly glamorous and festive. And since Carrera herself identifies as transgender and Latina, her attendance at the event and her involvement in the campaign suggested that “Play Sure” aimed to reach these often under-served populations.

To be sure, Ending the Epidemic organizers and Task Force members have made an effort to reach out to a variety of populations, and particularly people who identify as transgender, and to include these perspectives in the campaign. For example, the Task Force initially included at least one member who identifies as trans-masculine, but no transgender women. A known trans-female advocate was then brought onto the Task Force and, following complaints from other trans advocates that the Blueprint still didn’t fully address their needs and perspectives, a special trans-focused committee formed to oversee Blueprint implementation after the document officially launched. Since Ending the Epidemic relies so heavily on epidemiological data, one reason for such a delayed response to the trans community may be due to a dearth of information.

Still, when I emailed William, a prominent trans-masculine activist in New York City, to ask what he thought were the major challenges facing transgender populations in this campaign, he replied, “Some common challenges are the lack of an effective preventative message for Trans men…While more attention is being paid to Trans women than before, little to none
focuses on Trans males.” Cassie, who identifies as a transgender woman and works at a transgender-focused clinic in the Bronx, corroborated William’s claims. Cassie’s clinic runs a special program that focuses on transgender men, which she says they developed “…to ensure that we get more information about health disparities when it comes to trans masculine individuals, because we normally hear about the trans women.”

**Risk: For Whom & By Whom**

*Who Is “At Risk”? Who Is “Risky”?*

As most advocates and healthcare providers who are familiar with PrEP will say (e.g. Stephanie above), PrEP is not necessarily for everyone, but for those who are “at risk” for contracting HIV. And one’s level of riskiness often is associated with gender and race. Men often are thought to be more sexual than women and to maintain an increased level of sexual interest and ability during the course of their entire lives, as evidenced, for example, by the popularity of drugs like Viagra (Potts et al. 2006; Tiefer 1986). In addition to being male, men of color, and particularly black men, live in the popular imagination as people who are hyper sexual. Further, black male hyper sexuality often is considered dangerous. In a piece for *The New York Times Magazine* titled “Last Taboo: Why Pop Culture Just Can’t Deal with Black Male Sexuality,” Wesley Morris details the history behind fears of black male sexuality in the U.S., and particularly the black penis. Outlining famous cases in which black men were lynched for alleged crimes against white women, Morris writes, “The warning in these stories is obvious: Be careful near white people. The warning between the lines isn’t hard to spot, either: Be careful because your sexuality, to them, is hazardous” (2016). Indeed, a 2014 study in the U.S. showed that a group of medical students felt black men were more likely to engage in risky sexual
behavior while using PrEP than were white men, which made the medical students more inclined to prescribe PrEP for white men over black men (Calabrese et al. 2014).

Historically, this sense of danger has come from fears around the “black rapist” and accompanying miscegenation under slavery in the U.S. (Gunning 1996; Wiegman 1993; Davis 1981a) as well as under European colonialism (Stoler 1989; Spivak 1988). And it should be noted that in most of these scenarios white women are seen, on the one hand, as the victim of over-sexualized black men. On the other, they willingly desire sex with black men, thereby putting their relationships with white men at risk and undermining white masculinity. Viewed through this lens, black male sexuality is risky on a couple of levels: it threatens race identity through mixing races and it threatens the gender order by undermining white masculinity. As Wesley Morris writes, “…a black penis is mysterious only to those who don’t have one…Black male sexuality is of interest in American popular culture only when the people experiencing it are white.” Indeed, di Leonardo (1997) agrees that myths about the black “underclass” often are “standard white scripts” that pervade the media and therefore popular imagination.

While black men have long upset the gender order by being (seen as) almost hyper-male, black women historically have threatened the gender order by being simultaneously feminine and masculine. Under slavery, women were expected to work like men in the fields, but also to keep house, bear children, and submit to their masters’ sexual advances (Mullings 2005; Davis 1981a). Indeed, popular images of black women have long occupied an exotic and sexualized space in the “Western” imagination. For example, the Hottentot Venus; a Khoi woman from southern Africa who was paraded around Europe as a freak show act, and whose buttocks and genitalia were put on display in Paris’s Musee de l’Homme after her death in 1815 (Crais and Scully 2008). There are numerous other examples from colonial literature and beyond. However,
even when they are portrayed in the role of wild temptress (Thompson and MacAustin 2000), black women tend to be subsumed as objects of the male gaze, ultimately under the control of male power. In this respect, they may not be as risky as black men.

Perhaps because men have social permission to be sexual in a way that women do not, they also are seen as more sexual beings who are more willing to take risks or make “bad” decisions to fulfill their desires (Hirsch 2009; Gutmann 2005). Sex and sexual desire are naturalized in men in a way they are not for women. As such, sexual risk isn’t something that often is associated with women. In fact, one participant at the Ending the Epidemic implementation meeting in Buffalo pointed out that much of the messaging around PrEP focuses on MSM with the underlying assumption that these men have many sexual partners. Conversely, the participant noted, this messaging also assumes that women do not have many partners. This sentiment is echoed in an August 23, 2016 blog post by the Sophia Forum, an advocacy organization for women living with HIV in the UK. Responding to a series of social media conversations around women and PrEP, the Sophia Forum board wrote:

> Somehow there appears to be little space to even consider the notion that women may also be risk takers. When women say “We should be part of this debate because we too are risk takers, we too are drug takers, we too enjoy casual sex”, somehow these words are not heard… No one group’s risk should be placed above another. It makes no equitable sense nor is it safe to do so. Like anal sex or drugs, risks are enjoyed across the board. But according to the current dialogue apparently women do none of these things; we have safe sex and take few if any drugs…. Sophia Forum wholeheartedly supports the introduction of PrEP but we feel we cannot stand by and watch as women are denied the right to own their own risk. [http://sophiaforum.net/index.php/2016/08/23/women-seen-but-not-heard-in-the-prep-debate/; emphasis my own]

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24 Here I use “natural” the same way that Judith Butler does in her classic book *Gender Trouble* (1990). Butler suggests that gender identity is not in fact “natural” in the sense that it is biologically ingrained, but that gender roles are performed so much and for so long that they come to *appear* biological. Butler later acknowledged that biological difference cannot ultimately be ignored (1993), but her point that there is a fine line between biological and social programming remains relevant. In this vein, I like Ann Fausto-Sterling’s contention that, at the end of the day, we are “always 100 percent nature and 100 percent nurture” (2005: 1510).
As both the Sophia Forum board and the Buffalo meeting participant point out, when it comes to discussing PrEP, and even sex in general, women are not allowed to be risky. And if risk isn’t recognized, then opportunities to reduce HIV transmission are reduced.

Of course, one exception to this rule is female sex workers, who certainly have been singled out in the literature and in public health programming as a high-risk population (Vanwesenbeeck 2001). Early in the AIDS epidemic some countries, such as Thailand, even focused their HIV prevention efforts on the commercial sex industry as a whole (Wiwat 2006; Wiwat and Hanenberg 1996). Since about 2008, this focus has expanded to pay greater attention to transgender sex workers, and particularly those who identify as female (Operario et al. 2008). In some respects, this expansion signals attention to the needs, and indeed the very existence, of some women who had long gone unrecognized in the public health world. However, it places them in the historically stigmatized category of “sex worker.”

Sex workers are singled out as “risky” in terms of their potential to contract HIV and then pass it on to others outside of the defined group. In this regard, their very being is considered risky, not just their sex practices. Ironically, while it is important to recognize the legitimacy of sex work as a profession and to affirm the rights of those who engage in it, it is important to note that many people engage in “survival sex” work or are trafficked into the sex trade due to structural vulnerabilities such as poverty, youth, and homelessness (Chettiar et al. 2010; Marshall et al. 2010). This is particularly true of women, both cisgender and transgender (Shannon et al. 2009; Brennan 2004; Lombardi et al. 2002; Kulick 1998; Farmer and Connors 1996). These people certainly cannot own their risk and are in fact at great risk themselves for violence and adverse health outcomes due to their vulnerability in a trade that already is criminalized. As Fred put it during the November 18th Task Force meeting, “Let’s face it,” data on transgender women
are poor and data on sex workers is nonexistent. Indeed, it can be very difficult to collect reliable data on people whose very identities are at best extremely stigmatized and at worst criminalized (Shaver 2005), making them both more vulnerable to health issues like HIV and less likely to be adequately “seen” by a state-run campaign like Ending the Epidemic.

Further, while gender identity transcribes risk, non-heterosexual identities often are seen as especially risky because they upset the order of the heteronormative “caste system” (Weiss 2001). While gender identity may be socially constructed (Kessler and McKenna 2006), as Butler (1990) notes we must constantly prove our gender identity through our actions, many of which are associated with a heterosexual norm. In this case, a man having sex with a man, for example, upsets that established social order and therefore brings a man’s gender identity into question as well. Indeed, Foucault (1978) has postulated that sexuality is one of the essential means through which modern society is regulated and that non-conforming practices and identities, such as homosexuality, are considered subversive and threatening to the established power order. However, it also is worth noting that risk is not only an identity attached to MSM, but that men who identify as gay often take public ownership of their active sex lives in a subversive turn against social desires and expectations. As Douglas Crimp writes at the end of his article “How to Have Promiscuity in an Epidemic” (1987), for example, “Having learned to support and grieve for our lovers and friends; having joined the fight against fear, hatred, repression, and inaction; having adjusted our sex lives so as to protect ourselves and one another – we are now reclaiming our subjectivities, our communities, our culture…and our promiscuous love of sex” (270).

When multiple “threatening” identities are in play, a person becomes especially “risky.” People of transgender experience are especially threatening to the established social order due to
their potential to upset norms of both gender and sexuality. For example, how does one classify a transsexual woman who identifies as a lesbian (Raymond 2006)? This risk combination also works when race is involved. Although expectations of masculinity differ by race (e.g. black men are expected to be interested in fashion while white men are not) (Pascoe 2005), masculinity always is tied back to expectations around sexuality and sexual practices. Since black men, for example, are expected to be hyper-masculine, homosexuality among men of color upends these expectations (Ward 2005). The stigma that accompanies these threatening identities encourages people to keep their true selves hidden by going on the “down low” (Malebranche 2008; Ford et al. 2007) or by “passing” as cisgender and straight (Garfinkel 2006; Spradlin 1998). We can see also that although certain stigmatized identities have become more socially acceptable over time, this is true much more so for white people than for people of color (Daniels 2016).

In sum, by upsetting racialized, heteronormative power structures, certain identities already are considered “risky” even before a person engages in any sexual acts that might actually put them at risk for HIV. Many of these identities (transgender people, MSM of color) are exactly the populations that Ending the Epidemic specifically aims to reach with PrEP messaging and access. The ways in which PrEP users themselves portray their own gendered identities, examined further below, tells us more about the role of race, gender, and sexuality in framing EtE efforts.

*Gender, Sexuality, Race & Risk: PrEP Rally 4*

These patterns of association between gender, race, sexuality, and risk are well illustrated by both the PrEP rally for women described above, as well as by another panel I attended in the context of the Ending the Epidemic campaign. During the course of our discussion about two years after the women’s PrEP rally, Emily reflected back on the event, saying:
I do remember we had a woman who identified as lesbian who stood up at the very end during the Q&A and said, “As we’re talking about PrEP, we also need to talk about women who identify as lesbian or bisexual”…I think that this woman really brought up a good point that people make assumptions about people in their sex lives by, you know, like “Oh, why would a lesbian be at risk for HIV?” Well, you’re making assumptions around risk based on somebody’s sexual orientation…

The panelists who use PrEP themselves also provided interesting examples of popular expectations around gender and risk. In contrast to the way in which gay men and MSM often are portrayed as sexually promiscuous, thereby justifying their need for PrEP, two out of three women who appeared on the panel at the PrEP for women rally were in (ostensibly) monogamous heterosexual relationships. These also happened to be the women who participated in the event via phone, although one woman, Poppy, was calling in from California and perhaps couldn’t travel to be present. The other woman, Jasmine, was a local New Yorker who used a pseudonym for the event and did not want to appear in public to discuss her PrEP use. In both cases, the women were in monogamous relationships with HIV-positive men and they had chosen to start PrEP within the context of these relationships. For Poppy, she and her husband specifically sought out PrEP in order to conceive, and she gave birth to an HIV-negative baby girl in 2013. As she told her story, Poppy became noticeably choked up telling the audience that her daughter’s life would not have been possible without PrEP.

By positioning herself as a mother, Poppy assumed the role most socially acceptable for women and therefore seemed to justify her PrEP use and her risk by taking on this desired female identity. Still, Poppy recounted her first visit to a physician to ask for PrEP, where “I brought articles for her to read…contacts for her to call and talk to.” Poppy’s doctor then told her she wouldn’t see Poppy as a patient anymore “Because I was going to be engaging in unethical and risky behavior.” Poppy was clearly outraged by this encounter and ultimately sought out a
new doctor who listened more openly to her concerns and provided her with a prescription for PrEP. But this initial encounter clearly weighed on her.

The third woman on the panel who is currently using PrEP was Julie, an educated apparently middleclass white woman. Although Julie was the only PrEP user to appear in person at the rally, she was clearly nervous while taking the stage. Differentiating herself from Poppy and from Jasmine, Julie said to the audience, “I’m in a very different position…I’m a single woman…I’m not a monogamous woman and none of my partners are either, monogamous. So, there’s a whole network of exposure.” Further, she went on, “I don’t have the same family-positive moving story” like the one Poppy shared about conceiving her child. While Julie appeared to be comfortable with her sexual identity for the most part, this was an interesting moment where she clearly felt she almost had to apologize for her own story of promiscuous sex.

However, Julie went on to talk about the way in which her own acceptance of her sexuality and sexual risk has allowed her a level of freedom through PrEP that she was never able to realize before:

…there is this way in which 30 years of fear and resentment have dropped away. Here I am old enough to be a grandmother and I finally get to be the sexual person I knew I was at 18 [from the audience: “You go, girl.”] And I might cry a little [choking up] cuz that’s been a huge huge discovery…I was able to go to my primary care physician…What she said was, she wished other patients were as cold-blooded about their risk assessment as I am [laughter].

In some respects, all of the women PrEP-users on the panel were “cold-blooded about their risk assessment,” since each accepted her own participation in “risky” behavior and sought out a PrEP prescription as a result. However Poppy, the HIV-negative mother, was clearly outraged that a physician would refer to her sex life with her husband as “risky,” while Julie seemed to accept and even embrace this term. To be sure, Poppy was not treated with the respect she deserved in her physician’s office, but her reaction juxtaposed with Julie’s reaction seems telling;
sex within a heterosexual, monogamous relationship for the purposes of conceiving should not be considered risky. In contrast, although Julie told the audience that she was an “adherent” of the “religion of latex” that she learned in college, “And taking PrEP hasn’t changed that. I take my medication every day. I still use safer sex practices…,” her sex life must necessarily be considered risky because it does not fall within the bounds of heterosexual monogamy.

*Gender, Sexuality, Race & Risk: Community PrEP Panel*

This point also is illustrated by an example from a panel on PrEP that I attended at The LGBT Center (The Center) in late 2015. The panel featured speakers from The Center, the NYC Department of Health and Mental Hygiene, a local health center sponsoring the event, and two PrEP “consumers;” one a black transgender woman (Lily) and one a Latino man who identified as MSM (Hector). Of all the EtE-related events I attended during the course of my fieldwork, this was one of the most striking. Upon arriving somewhat early to the event, I took a seat in front of Lily, not realizing she was going to be speaking, and struck up a conversation. During the course of our conversation I learned that Lily worked with an organization that does outreach to transgender sex workers and she also told me that she was nervous to speak in front of a room full of people. It seemed public speaking wasn’t something she did often. Yet, the panel was notable for the candidness with which Lily and Hector spoke about their experiences with PrEP, sharing some of the intimate details of their romantic lives with a room full of strangers.

The panel also was striking for the ways in which both PrEP users enacted and reinforced their gender identities through their discussions of PrEP. As I wrote in my fieldnotes from this event, “It almost felt like watching a performance of the extremes of our expectations of gender, masculine vs. feminine, played out by two people who society says should not be examples of these very identities.” Lily described a series of relationships with men (one of whom was HIV-
positive) who may have had other sexual partners at the same time. So, Lily told the audience, she decided to start taking PrEP to keep herself safe. Lily’s tone while telling her story was intimate and vulnerable, painting a picture of herself as largely lacking control in her romantic relationships and using PrEP to keep herself safe from the men who might harm her. In short, Lily came across as an extreme version of the feminine ideal.

Hector, on the other hand, portrayed himself as a hyper sexual, promiscuous gay man. In contrast to Lily, who seemed small and quiet onstage, Hector was loud and gesticulated wildly with his hands. He detailed the sheer amount of sex he was having and described how labeling himself “on Truvada” on a popular hookup app resulted in more men asking him to have condom-less sex. After contracting other STIs while having sex without condoms, Hector decided to stay on PrEP without publicizing his status to his sexual partners. So, Hector conveyed the message that he was practicing safer sex after some negative experiences, but not that he had decreased his number of partners.

Further emphasizing the point that MSM are promiscuous and are in fact expected to be hyper-sexual, during the question and answer portion of the event an audience member stood up and read aloud into the microphone from a hookup app on his phone. Like Hector, this man had publicized his “on Truvada” status on the app and shared a PrEP-related exchange he’d had on the app with the whole room. Also like Hector, the audience member’s tone (and indeed, his desire to share these messages at all over a microphone) while sharing was brash and dramatic. Both men were claiming their right to be sexual and to talk openly about sexuality, which often is a trend in the AIDS world: at ACT UP meetings, sexual references are bandied around; at one NY Knows event in late 2014, Demetre Daskalakis joked that his department would be holding a “flaccid launch” of the NYC condom at an upcoming World AIDS Day event. As many Ending
the Epidemic participants point out, social discomfort with sexuality and discussing sexuality in public is one of the main barriers to effective HIV prevention. So, using this kind of language in public forums can be a way to promote more open discussion around sexuality and (ideally) advance the HIV prevention agenda (Guzmán et al. 2003; Gupta et al. 1996). However, the references are most often to male genitalia and often with homosexual undertones.

Toward the end of the PrEP event one of the panelists, a transgender woman who works at The Center, noted that “some groups aren’t allowed to brag about sex.” At the time, I wasn’t sure if this comment might be a broad statement about how LGBTQ people are not supposed to talk about sex or sexual health. But I felt that it might instead be a veiled reference to the difference in tone between the two PrEP users on stage. While Hector was able to brag openly about his sex life, Lily felt she had to frame herself as a victim of the promiscuous men she was sleeping with. Lily also underscored her romantic feelings toward these men, suggesting that she was not having the meaningless and anonymous sex that Hector seemed to wave in front of the crowd. As evidenced by some of the literature on AIDS activism, although gay men involved in the movement historically have been disadvantaged due to their sexuality, at the same time they have enjoyed the social privilege of being male (e.g. Epstein 1995). This differential privilege certainly extends to sexual behavior and seems to apply here. Since Hector identifies as male, he has the privilege of speaking loudly and openly about his promiscuous sex life, while Lily identifies as trans-female and must emphasize her physical and emotional vulnerability when it comes to sex.

In both this panel and the PrEP rally for women, then, the extent to which a person is “allowed” to be sexually risky is transcribed by their gender identity, race, and even class. During the PrEP rally for women, Poppy positioned herself as less risky than others due to her
heterosexual and, we are led to believe, monogamous relationship status, and seemed to justify her risk through her new identity as a mother. Meanwhile, although Jasmine also is in a heterosexual and ostensibly monogamous relationship, she receives PrEP through Medicaid, which appears to put her in a lower socioeconomic class position than either of the other two panelists. So, it is noteworthy that Jasmine gave the shortest presentation during the panel and seemed most interested in preserving her anonymity in relation to her PrEP use. Julie, who is white and appears to be middle class, was most public about her risk, but still felt she needed to apologize to the audience for not having a “family-positive moving story” to justify taking PrEP. Similarly Lily, a black transgender woman, felt she needed to position herself as loving and monogamous, but vulnerable to male partners who might be seeing other women. In contrast, Hector, a Latino man who identifies as MSM, felt justified in sharing his story of promiscuous sex with a room full of strangers. In this case, Hector’s identity as a cisgender man of color, and particularly as a man who has sex with other men, was justification for his “risky” behavior.

However, Hector’s residence in New York City and his work in the nightlife industry might also explain the privilege he enjoys when it comes to being open about his sexuality. The July 2015 Blueprint implementation launch event in New York City similarly featured a panel titled “MSM and Transgender People of Color – What works for populations at risk?” The panel was moderated by Damian, a Task Force member who identifies as an MSM of color living in New York City, and two panelists who identified as MSM of color (a third transgender panelist was running late and had to miss this particular panel). One of the panelists, a black resident of New York City, was open about his history of drug use and his sexual practices. The other, a younger black man who lives outside the city and works in healthcare, seemed uncomfortable participating in the discussion and seemed eager to distance himself from any association with
risky sexuality when he recognized that, while random hookups sometimes happen, “I’m not saying that happens with me.” This young man’s ability to own risk, or not, may have come from his residence outside of New York City, where residents tend to have more conservative social views. Further, in contrast to the panelist who identified as a former drug user, this panelist was neatly dressed, told the audience he worked in healthcare, and clearly conveyed a middleclass identity. As Bourdieu (1977) tells us, class status is heavily tied to comportment. This is particularly true for men of color, who must work extra hard to overcome the racial bias that can stand between them and a desired class association (Hochschild 1996). The panelist, then, may have been working to distance himself from a “risky” identity partially as a move to associate with a particular class status as well.

**Risky Sexuality Is a Medical Condition**

As exemplified by the autopsy that resulted in the Hottentot Venus’s genitalia being put on display in Paris (above), sexuality has long been seen as a sort of medical condition. This is particularly true when it comes to the types of sexuality that often are seen as abnormal or risky. For example, homosexuality was notoriously listed as a pathology in the second edition of the American Psychiatric Association’s *Diagnostic and Statistical Manual* (Drescher 2015). Indeed, since this listing in the DSM was seen as contributing to social stigma toward gay people, much early gay activism revolved around de-medicalizing homosexuality (Drescher 2010; Kameny 2009; Gittings 2008). While this activism ultimately proved successful with the removal of the condition from the DSM in 1973, it is ironic but not surprising that a similar battle is now being waged over “Gender Dysphoria.” According to the DSM-5, “For a person to be diagnosed with gender dysphoria, there must be a marked difference between the individual’s expressed/experienced gender and the gender others would assign him or her…” (American
Psychiatric Association 2013). Essentially, it is a diagnosis of transgender identity. While Gender Dysphoria was included in the DSM partly as a way to increase access to health services for transgender people, scholars and activists point out that labeling transgenderism as a medical condition raises some of the same concerns that gay activists raised in the 1970s (Drescher 2010; Rosenblum 2000).

Some have argued that homosexuality became re-medicalized in the era of HIV/AIDS, because being gay was seen as a symptom of the virus (indeed, HIV/AIDS was first known as Gay-Related Immune Deficiency, GRID) (Kayal 1993). As Treichler (1988) notes, due to this early association between AIDS and homosexuality and the fact that AIDS scientists initially were largely ignorant of male homosexuality, “The subsequent scientific and medical obsession with the details of male homosexual practices was in part a compensatory by-product” of this ignorance (199). While some would say that homosexuality has since been de-medicalized (Conrad and Angell 2004) yet again, there is certainly no denying the strong connection that persists between homosexuality and HIV/AIDS both in the medical literature and in the public health imagination. Further, Rosenberg (1986) points to the irony that the same activists who once advocated for the de-medicalization of homosexuality anxiously engaged with the medical establishment once AIDS was discovered. More recently, technologies such as HIV treatment as prevention (TasP) and PrEP certainly have re-medicalized HIV/AIDS itself by offering a pharmaceutical solution to a problem that has much larger social causes and implications (Giami and Perrey 2012; Nguyen et al. 2011).

**Tracking Medical Risk: The PrEP Registry**

As noted in Chapter 4, one of the main obstacles to adequately rolling out PrEP is the dearth of information around actual PrEP use and potential PrEP candidates, since so many come
from stigmatized populations. At the October 2014 metrics meeting Tim, a young activist from ACT UP, presented an idea he had developed with another ACT UP member to create a PrEP registry using Medicaid data. The proposed registry was meant to fill a gap in the available data that could then help the state direct resources to the most appropriate sub-populations and determine PrEP’s cost-effectiveness. At the time this proposal provoked few responses, except for a comment made by an attendee from the CDC who said that the idea of creating a database of people who are engaging in highly stigmatized behavior “Makes me nervous.”

This same proposal was later put forward by the Data sub-committee of the EtE Task Force at the November 18, 2014 meeting, and this time it received a little more pushback from the full group. During a breakout session for the sub-committees to meet amongst themselves, conversation in the Data sub-committee focused largely on the feasibility of creating such a database, particularly what kinds of data exist beyond Medicaid and how to bring these sources together in a useful way. As the group debated how to create the registry, one sub-committee member asked, “Is there an example of anything [like the PrEP registry] in public health?...We don’t have a birth control registry, for example.” This comment prompted much laughter from the women in the room. Another participant then pointed out that the data available is for people who are in care, but not necessarily for those who are “at risk.” Thinking aloud about models for tracking people who are at risk in public health, he joked, “Anyone have friends in Dallas?” and the group chuckled. At this point in time, western Africa had been hit by a particularly violent outbreak of Ebola and a few cases had been identified in the U.S., prompting public health personnel to judiciously track potential Ebola patients. Incidentally, a number of AIDS activists compared the Ebola “witch hunts” to the U.S.’s original paranoid response to HIV in the 1980s (Wainberg and Lever 2014).
When the Data sub-committee shared their preliminary Blueprint recommendations out to the full Task Force later in the day, one participant responded “The word ‘registry’ I think sends chills down the spines of many of us,” since registries like the one proposed historically have been for people who don’t “follow the rules.” This comment seemed to resonate with a number of people in the room, but the recommendation still made it into the final version of the Blueprint. Blueprint Recommendation number 14, “Develop mechanisms to determine PrEP and nPEP usage and adherence statewide” reads:

Since PrEP and nPEP has been identified as one of the three major initiatives in the plan to end HIV as an epidemic in New York, it would make sense to develop as comprehensive a system as possible to determine how many persons are on the medication and how adherent they are…The state has good direct access to information of [sic] how Truvada® is being used by persons on Medicaid, but not so for other payers. The manufacturer of Truvada® only provides estimates of PrEP and nPEP utilization based on sales at a sample of pharmacies nationally. The possibility of creating a registry for the purposes of monitoring usage and adherence among New Yorkers is one avenue that should be explored. [New York State Department of Health 2015: 24; emphasis my own]

Despite the inclusion of the proposed PrEP registry in the final Blueprint, it appeared for awhile that the registry ultimately was not going to be realized. However, a blog post on the Ending the Epidemic Dashboard site from November 2016 notes that the AIDS Institute did pull from the Medicaid database to track the number of PrEP prescriptions filled by Medicaid since 2012. The Dashboard site allows users to view this data by age, sex, region, race/ethnicity, and Medicaid program.

Not only does a PrEP registry feel particularly Foucauldian (see page 15), but it also seems to speak to the racialized history of medical experimentation discussed in Chapter 4. As one of the panelists at the community PrEP panel noted, in communities of color, new pharmaceuticals and medical technology always raise the specter of Tuskegee. The off-hand joke about a “birth control registry” also is relevant in this context, since the underlying message is
that women haven’t been tracked for their risky sex lives, but they could be (the parallel between PrEP and birth control is explored further below). In short, risky sexuality is framed as a condition that is traceable and recordable, but many of those who stand to be traced already have reason to fear greater reach into their private lives by the state and the medical establishment.

**Tempering Risky Sexuality with Drugs: Birth Control Parallels PrEP**

If sexuality is a medical condition that can be tracked, then it comes as no surprise that certain kinds of sexuality can be “treated” with drugs. One of history’s best examples of this kind of treatment is oral contraception, or, “The Pill.” Since PrEP is still a relatively new technology, Ending the Epidemic participants working in the field of HIV prevention regularly face the conundrum of how to explain PrEP in a way that is meaningful to potential patients. For most of them, drawing a parallel with The Pill seems to be an effective way to do this. As Christina, a young advocate herself who works with youth in schools told me:

Christina: Sometimes we like to…compare [PrEP] to birth control, which makes it easier for [students] to understand.
Interviewer: How do you do that?
Christina: We basically say ‘PrEP is like birth control. You take it every day. And PEP is like the morning after pill.’ And then they’re like ‘Oh, ok. That makes more sense.’

Indeed, the mass media has drawn similar parallels (Morgan 2013; Sharrock 2008), as have prominent advocates involved with EtE such as Stephanie. Responding to my question about how much she thinks average New Yorkers know about PrEP, Stephanie said, “…if you go out and ask 10 people on the street, how many would know about PrEP vs… how many would know what The Pill is? Everybody would know [about The Pill].”

In addition to using The Pill as an explanatory framework for PrEP, those involved with Ending the Epidemic also draw a more specific parallel to the element of sexual risk-taking that is implied with both prevention technologies. At an EtE implementation meeting in Rochester,
Charles King proclaimed, “PrEP does not mean you’re a slut. PrEP does not mean you’re a whore anymore than birth control means you’re a slut.” In addition to drawing a parallel with historical debates about birth control, in this comment Charles nods to the popular fear that, with the advent of PrEP, MSM would become “Truvada whores” having promiscuous unprotected sex and spreading disease all over town. While the evidence thus far varies in terms of whether or not this “risk compensation” is merely theoretical or actually occurs (Calbrese et al. 2014; Marcus et al. 2013; Golub et al. 2010; Guest et al. 2008), research is still under way in this area and the idea of the Truvada whore persists in the popular imagination (Burress 2014; Duran 2014).

Taking a more nuanced approach, Dr. Rivera described to me how she works with young people who are good candidates for PrEP:

And particularly with adolescents…[it’s the] same discussion as around birth control, young people are not, have a hard time conceptualizing or taking ownership of the fact that they’re being sexually active in a risky way. And that’s for many many reasons…We often shame them. Parents tell them that they’re not supposed to, particularly if they’re gay. So, there’s a lot of reasons not to take ownership of that reality. And you don’t take ownership of something until every day is really really challenging, which is also part of the reason why, for example with birth control, we do try to encourage patients to use long term acting contraception…We don’t have that yet with PrEP…

In other words, both technologies are associated with sexual risk and associated shame, and both Charles and Dr. Rivera recognize that potential PrEP users may shy away from the drug due to this association. Further, Dr. Rivera points to pills, whether birth control or PrEP, as a physical manifestation of risk; people who take birth control and/or take PrEP may not want a daily reminder that they are engaging in potentially risky sex.

However, certain types of risk are more acceptable than others. In an apparent reversal of attitudes toward sexual risk-taking in men versus women, oral contraception has become a (largely) accepted form of risk mitigation while PrEP does not yet enjoy this level of
acceptability. A good example of this is the way in which state government provides financial assistance for family planning. In my discussion with Dr. Rivera she pointed out one of the fundamental differences in access to contraception versus access to PrEP, particularly for young people:

> And PrEP is not covered under the…Family Planning Benefits program…Every provider in any kind of conversation that I’ve gone to around this have asked about whether or not it is. Because, for example, with [inaudible], even if a patient has insurance, particularly if it’s through their parents…maybe if it’s unsafe for them to use their parents’ insurance, but they need to get preventative reproductive health services and apply for it, but we can’t do that for PrEP…HIV testing is covered in there, but not PrEP.

New York State’s Family Planning Benefit Program covers family planning services for state residents who are not otherwise enrolled in Medicaid and, as Dr. Rivera pointed out, this program covers HIV counseling and testing, as well as testing and treatment for other STIs. However, it does not cover PrEP (or, indeed, nPEP). Perhaps PrEP is not yet covered under the Family Planning Benefits Program because it is still somewhat new, but the fact that the state does not consider PrEP to be a family planning technology in this particular case is noteworthy. Indeed, PrEP is recommended for serodiscordant couples who are trying to conceive naturally (CDC n.d.). So, by providing financial assistance for contraception but not for PrEP, the state seems to accept that women may engage in sexual behaviors which put them at risk for an undesired pregnancy, but not that they might risk getting HIV in order to get pregnant. This theory certainly dovetails with Poppy’s story above.

> Indeed, The Pill and PrEP ultimately are very different prevention technologies with different gendered meanings attached to them. The Pill often is credited with facilitating the sexual revolution of the 1960s in the U.S. by allowing women to have sex for pleasure without the fear of an undesired pregnancy, although early media coverage took a moralistic stance against this (Eig 2014; Bailey 1997; Asbell 1995). These concerns certainly parallel the
moralizing “risk compensation” rhetoric that has arisen around PrEP as described above. Still, after all of the concerns around women’s sexual freedom, now there is much research suggesting that The Pill actually depresses a woman’s sex drive (see for example Sanders et al. 2001; Graham et al. 1995; Bancroft et al. 1991). Perhaps unsurprisingly, it turns out you can “treat” women’s sexuality with drugs. Although it may well be true that an increase in female hormones like estrogen has the effect of reducing sexual desire, I suspect Emily Martin (1991) would not be at all surprised by these findings; that scientific research on a technology initially thought to promote women’s sexual liberation ultimately affirms the long held idea that women, and their hormones, are less sexual than men.

More recent scholarship on the HPV vaccine, initially outlined in Chapter 4, offers a similar view. Social scientists point to the ways in which the HPV vaccine has been framed by pharmaceutical companies and by the media as a vaccine against cervical cancer in an attempt to de-couple the vaccine from its associations with a sexually transmitted infection (Gottlieb 2013). De-sexualizing the HPV vaccine is particularly important because it initially was released only for young women and girls and, following historically gendered scripts, advertisements for the vaccine framed these populations as both at risk and vulnerable to sex, rather than as conscious sexual beings (Aizpuru 2015; Fickley-Baker 2012; Mishra and Graham 2012; Conrad 2011). Although the vaccine has since been approved for young men, this early framing exhibited a “double standard” when it comes to the sexuality of young women versus young men (Carpenter and Casper 2009) while also creating the idea that young men are not “at risk” for HPV in the same way that young women are (Pisciotta 2012). In contrast, the very existence of drugs like Viagra for men and accompanying advertisements that send messages of virile masculinity
emphasize that men must be sexual, and when they are not this condition can be treated with pharmaceuticals (Vares and Braun 2006; Mamo and Fishman 2001).

Since, like The Pill, PrEP is seen as a drug that promotes sexuality, it must therefore be for men and not for women. And so it comes as little surprise that the Ending the Epidemic campaign promotes this message. However, the commonly drawn parallel with The Pill is interesting. In fact, as Myers and Sepkowitz (2013) point out, we knew far less about the safety of The Pill when it was released than we do about Truvada, which has been used for a long time in HIV-positive patients. In effect, women were pharmaceutical guinea pigs in this case much more so than are the men to which PrEP is now being peddled.

*Medication Adherence: Gendered Expectations*

Perhaps more importantly, as one of my interviewees pointed out, gendered expectations around health and health-seeking behavior informed these two technologies from the beginning. As Jacob, a PrEP coordinator at a hospital in New York City, pointed out to me, women are often thought to seek out healthcare more and to be better patients than are men (and there is some evidence to support this, such as Smith et al. 2006; Galdas et al. 2005). By extension, women should be more adherent to medication regimens like The Pill, which, more than 50 years after approval by the FDA, must still be taken daily. A woman must be responsible about treating her sexual risk with drugs. And notably, a contraceptive pill never has been developed for men. This may be partly because men are not expected to be good patients or to be adherent. So, less than five years after Truvada was approved as PrEP, studies already have proven that PrEP can be taken irregularly and still be effective (Molina et al. 2015). This makes it seem particularly

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25 Indeed, as much as we get this message through the Ending the Epidemic campaign itself, even the scientific literature on PrEP so far tells us that it mainly is for men and that prevention options for women, like a microbicide or the female condom, are inferior (see for example Marrazzo et al. 2015; Van Damme, Corneli & Ahmed 2012). See Stein 2011 for an argument against this view.
ironic, then, that women have been blamed for their lack of regular adherence in microbicide trials in southern Africa (Rees et al. 2015; Marrazzo et al. 2015; Van Damme et al. 2012).

Indeed, medication adherence is one of the big obstacles for the Ending the Epidemic campaign. Even if community-based organizations provide outreach and the state provides funding for medical services, and pharmaceutical companies provide medication assistance, people need to take the drugs in order for them to be effective. This has been a particularly important message for Ending the Epidemic, perhaps because medication adherence often is a sign of regular engagement in healthcare. And, as key EtE players like Demetre Daskalakis regularly point out, in some respects the real goal of the campaign is to get more New Yorkers into healthcare to improve overall population health and, by extension, reduce HIV transmission. ACT UP’s decades-old goal of achieving universal healthcare lives on.

Yet again MSM, and particularly MSM of color, are portrayed as a key population on which to focus research and PrEP adherence support. During many of the speeches he delivered at each Ending the Epidemic implementation meeting across the state, Charles King would note a recent study on PrEP adherence in which MSM of color never “reached the line” in terms of taking the drug regularly enough for it to be effective. Further, at least one study on adherence that is currently running in New York City, “PrEPared and Strong,” focuses solely on young MSM of color, offering them an enhanced intervention package to help them better keep up with the regimen. Indeed, as noted above, research conducted thus far proving PrEP’s efficacy when taken irregularly was conducted among MSM (Molina et al. 2015).

At one of the early Ending the Epidemic Task Force meetings, I ended up eating lunch with a member of ACT UP and discussing medication adherence. During this conversation, the ACT UP member told me he wants people to see HIV medication adherence as an “act of
grooming,” an “ablution,” suggesting that taking HIV drugs should be both a religious ritual and a mundane daily task. This comment struck me as both incredibly optimistic and somewhat naïve. The very problem with PrEP adherence, it seems, is that most of the people who struggle with it don’t even have a daily routine to adhere to in the first place. As Stephanie put it at the PrEP rally for women, “Adherence…is really the Achilles heel for PrEP efficacy.” She went on:

> Poor adherence appears to be the primary reason for the less than stellar outcomes of trials involving women…but as much we need to pay closer attention to the different ways in which men and women seek healthcare and the possibly different interventions and services that we need to wrap around PrEP to support adherence [for example, a woman might not be able to adhere to PrEP if she has childcare issues or unstable housing]. So, we to need just be more vigilant about demanding women-focused research to help us design programs and services that surround PrEP, the pill [and ensure that PrEP fits] in the context of her life.

As Stephanie points out here, PrEP adherence is bound up in the much larger structural issues that ultimately shape day-to-day lives. Issues like access to housing. Issues like affordable childcare. Further, research on PrEP adherence needs to pay attention to these issues in order to create a knowledge base that enables patients to take their medications in the context of their lives as they live them. Although Stephanie made these statements specifically in regard to women and in response to the “less than stellar” outcomes of PrEP trials focusing on women, surely these principles apply across the board. In the words of the Key Populations sub-committee co-chair, surely PrEP adherence is not about “who people are, but basically what they do” in contexts that put them at greater risk for HIV. While gay men have long been at the top of the hierarchy of risk associated with HIV, maybe it is time to re-assess the components of this hierarchy to begin with.

**Discussion & Conclusions**

*PrEP Is About Freedom & Choice*
Following the comparisons numerous Ending the Epidemic participants made between PrEP and birth control, I offer another parallel: PrEP is about sexual freedom and choice for those who haven’t had it before. Or, as Stephanie said it so well during the PrEP rally for women, “PrEP is about choice. It’s about sexual health. It’s about freedom.” During the rally, both Jasmine and Julie recalled growing up in the “fear generation” of the 1980s, before effective HIV treatment was available at all, let alone PrEP. As Julie told the audience, “I thought as a teenager college was gonna be lots of sex and great drugs [laughter from the audience]. It absolutely was not. It was a time of great fear.” In this respect, Jasmine noted, “Sometimes it feels too good to be true…I wonder, you know, even if you take all the precautions and condoms and PrEP,” suggesting both that she isn’t used to having this kind of choice and that she doesn’t yet completely trust it.

As noted in the Introduction, because much of the early organizing around HIV/AIDS sprang from the “Free Love” movement of the 1960s and ‘70s, sexual freedom has been a common theme in the AIDS world since the virus began. Since AIDS was associated with homosexuality early on, and gay men often are associated with promiscuity, AIDS was seen as a sort of curse of sexual freedom. Yet, the crux of this freedom isn’t about sexual acts themselves, but about the ability to be fully one’s self and to experience love, intimacy, and desire in all the ways that one needs. As Julie noted above, PrEP has finally allowed her to become the sexual person she always knew she was. Dr. Rivera also spoke poignantly to me about this topic:

So, I think part of what I had talked about was that…someone comes in asking me for PrEP and they don’t really have that much of a risk, and this is for example, true in serodiscordant relationships where the partner [of a patient coming in asking for PrEP], who I may be taking care of, has been undetectable for a really long time. There really isn’t a clinical reason for them to be on PrEP. But, it allows them this sense of control over their sexuality and ability to be intimate in a way that I think this population in particular deserves to have. And I think that that has value in itself.
Framed this way, Dr. Rivera suggests that PrEP use shouldn’t be only about risk, but about feeling comfortable and safe in an intimate relationship, regardless of whether or not a real medical risk is present. Since most of Dr. Rivera’s patients in Brooklyn come from Caribbean communities, she points out at the end of the above quote that people of color in particular may “deserve” to have an extra level of safety and security built into their romantic relationships when possible. Of course, from a public health perspective, and particularly the perspective of policy makers who must find money to subsidize PrEP use, it may not make sense to pay for people to take PrEP in cases where they legitimately are not at risk for contracting HIV. But, if we can make a case for reparations for African-Americans (Coates 2014), might something like a PrEP subsidy count toward balancing social inequities?

*Who Makes Choices?*

The real question, though, is much deeper. If, as discussed in Chapter 4, PrEP is a marketable drug, then there should be some level of choice involved in its consumption. Do those who are “at risk” for HIV align with those who have choice in the market? The answer is complicated. On the one hand, as one panelist noted at the PrEP panel held at The Center in September 2015, “If you overlay the maps of HIV incidence, prevalence, and poverty in NYC, you will see that they closely align,” and it certainly is true that poverty and HIV align far outside of New York City as well (Susser 2009; Farmer and Connors 1996). By definition, people living in poverty have far less purchasing power, and therefore choice, than others. Further, any potential association with HIV or other stigmatized behaviors (promiscuous sex, drug use) can put a patient’s credibility into question with a physician, who ultimately grants access to PrEP. After telling the story of her first physician who refused to treat her after she requested PrEP, Poppy reflected back on the experience:
I really wish...that first doctor who told me that she would not prescribe PrEP to me...was extremely disheartening and very discouraging...I didn’t understand her stance...It was really apparent to me that she felt she knew better...what would be the best decision and choice for my life. And it didn’t occur to her that this had been a decade-long process for my husband and I, and that we had done a lot of research...Overall, I felt that her, I guess I did not feel supported by her in the decision I was making. And I really was looking for her to reduce and to minimize the risk to myself and she kind of left me dangling with that...[emphasis my own]

Even in this case, where Poppy and her husband were clearly educated about their options and felt they were making an informed decision, Poppy’s physician refused to help her “minimize the risk to myself” because she didn’t trust Poppy’s opinion and knowledge.

For people who may be seen as even riskier and less “trustworthy” than Poppy, such as transgender women of color, their ability to make choices about their own healthcare is even less. Drawing on Colen’s (1995) concept of “stratified reproduction,” Davis’s (2009) analysis of the 2009 “Octomom” scandal strikes a chord here. In early 2009, Nadya Suleman gave birth to a set of octuplets, the second set ever born in the U.S. Initially lauded as a sort of miracle, Suleman’s delivery was quickly demonized in the popular media as reports leaked that she was on welfare, single, and already had six other children. Plus, as Davis (Ibid: 108) points out, Suleman’s name alone suggests she is not white. According to Colen’s theory of stratified reproduction, women who already enjoy a certain amount of privilege through their race and class status are better enabled and encouraged to have children than are poorer women of color who work, for example, caring for the children of white women. In her analysis of the Nadya Suleman scandal, Davis points to the mistaken assumption that all individuals have the same opportunities to choose the goods and services they access in the free market, and also that these goods and services will only be accessed by those who are “supposed” to have them. As Davis writes, “…‘choice,’ as I have argued earlier, can be conditional...In other words, ‘choice’ rests
on the availability of resources and sanctioned status; without resources and status some women are unable to actualize ‘choice’ in the same way that others might (Ibid.: 111-112).

Although Davis is talking about reproductive choice, herein lies the conundrum for Ending the Epidemic; those who are “at risk” are the same ones who have very little “choice” in the marketplace. To their credit, campaign organizers seem to recognize this challenge, which is precisely why they have focused their attention on populations that have limited access to the pharmaceutical market. However, here is where the problems of risk and choice are overlaid, turning the issue of choice as Davis frames it a bit on its head. As I argued earlier in the chapter, we all carry biases about risk based on prevailing social norms around gender, sexuality, and race. And similar to the argument I made in Chapter 3, while I recognize that statistics showing that MSM of color are a group deserving particular attention in HIV prevention work, I suggest that these deep biases inform the way the statistics are created and interpreted. For example, as Cassie told me during our interview (and this is no secret among Ending the Epidemic participants), transgender women often are counted as MSM in surveys, obviously skewing the MSM data. In turn, people who often are seen as risky or threatening for their sexuality (e.g. MSM of color) receive a historically unprecedented amount of choice in the pharmaceutical marketplace for PrEP. Meanwhile others who aren’t considered particularly risky don’t receive the same boost to their choices, while even others who historically have enjoyed a lot of choice (e.g. educated white women like Julie and Poppy) struggle to exercise it. This is not at all to say that increasing access to health services for anyone is a bad thing, and certainly women like Julie and Poppy had resources that they leveraged to gain access. It mostly is to point out that even when the system of choice is upended in some respects through this lens of “risk,” many of those who historically have been excluded from the AIDS conversation continue to be.
Maybe, then, the PrEP project is less about giving different populations options or choices, as it purports to be, and instead involves a hearkening back to the free love ethos of early AIDS activism. Framed this way, targeting PrEP marketing to certain populations over others makes much more sense. Men, particularly MSM and particularly men of color, are expected to be sexual, even if this sexuality is considered risky. I believe this expectation extends to transgender women of color since, as Morris (2016) points out, society fears the black penis almost independently of the person attached to it. Giving these populations access to PrEP allows them to be the free, sexually promiscuous people they are supposedly meant to be, while in turn opening up the partner pool for all MSM regardless of race. This would also explain the lack of attention to PrEP for women. Women still are not allowed free love, nor are we allowed sexual risk. Why should we be given sexual freedom in a pill?
CONCLUSION

“Not everything that is faced can be changed, but nothing can be changed until it is faced”
- James Baldwin in the documentary I Am Not Your Negro (Peck 2017)

In conclusion, what is at stake in examining the unequal power relations of a campaign to end the AIDS epidemic? Most importantly, we need to recognize that this is not actually the end. As many Ending the Epidemic participants suggest, at best it is the beginning of the end. My goal in this dissertation has been to examine where AIDS activism stands now and how this can inform future movement toward the actual “elimination” or even “eradication” (Dowdle 1998) of HIV/AIDS, which may yet be decades (at best) away. To examine the extent to which Ending the Epidemic has been successful in addressing unequal power dynamics that have plagued the field for the past 35 years, I focused on key themes coming out of the literature on AIDS and social movements. In particular, I looked at the politics of organizing and politics of knowledge, as well as the literature on pharmaceuticals and feminist analyses of sex and the marketplace. I wanted to know how Ending the Epidemic was structured with regard to these themes, both at the highest levels of organizing within state institutions like the AIDS Institute and down at the level of grassroots organizing among service providers and outreach workers on the ground.

Chapters 1 and 2 examined the dynamics of Ending the Epidemic in its early stages, placing the campaign’s formation and the beginnings of its implementation phase in the context of key themes from AIDS activism’s long history. In Chapter 1, I discussed the dynamics of Ending the Epidemic’s formation in relation to the lived history of activists who have been in the field for a long time and who see this moment as one in which they strive to realize promises made to friends and loved ones long dead. The chapter follows the work of the Ending the Epidemic Task Force to produce a final Blueprint to End the Epidemic in January 2015, and
subsequent organizing to officially launch the Blueprint in April. In order to do this work, many activists who have been in the field for a long time drew on the strategic acumen, professional status, and thorough knowledge as “lay experts” (Epstein 1995) that they have built up over the past several decades. Conflicts that have long plagued the HIV/AIDS field as a whole, such as struggles around racial politics, as well as around the extent to which activists are willing to “play the game” in politics to achieve their goals, therefore arose in this stage of the campaign. I suggest that some of these pre-existing dynamics have been further institutionalized through the campaign, but in some areas we see progress in making change through, for example, the influence of young MSM of color like Damian.

In Chapter 2, I examined the early stages of Ending the Epidemic’s implementation phase with a focus on the ways in which the concept of “community,” an important concept in AIDS activism in general, was used to mobilize the larger campaign. The issue of who is in and who is out of the EtE community became especially relevant at various events sponsored by activists in New York City. These events demonstrated which communities continue to feel marginalized in Ending the Epidemic. Although some of these communities (e.g. trans populations) are increasingly gaining a voice in the EtE process, it is clear that within the campaign itself the white men who have long led the AIDS activist movement continue to enjoy these privileges. Now, however, there is a particularly pronounced disconnect between those who run the Ending the Epidemic “community” and those who must enact the provisions of the Blueprint in “communities” on the ground; the people of color, and particularly women, who disproportionately make up the health service field. This certainly aligns with anthropologists’ findings around gendered and racialized trends in care-giving in the U.S. and other high-income
countries across the globe (Vora 2015; Yeates 2008; Ginsburg and Rapp 1995; Brodkin Sacks 1987).

At this level, the spirit of community is often called upon to encourage service providers to “collaborate” as a means of managing shrinking budgets handed down by federal and state governments. And this type of encouragement may feel like an “unfunded mandate” to providers operating in a field where responsibility for healthcare is being de-centralized. When healthcare reform in New York State increasingly leans on providers to work beyond their job description and initiatives like EtE suggest that everyone in the community is responsible for the campaign’s outcomes, campaign efforts clearly are being enacted within a system that prizes individual responsibility while upholding the power relations that make it far easier for some to take responsibility for themselves and their “community” than it is for others. However, this may also be an opportunity to re-think activism in some ways by shifting the definition. If AIDS activism is no longer the “high risk” (McAdam 1986) street activism it once was and instead takes place more often in the workplace, perhaps now there is room to re-value the contributions of those who are active in the field in other ways, such as women and people of color.

In Chapter 3 I move to a discussion of another key theme in the history of AIDS activism: the politics of knowledge. Specifically, in this chapter I discuss the role of data and its generation, management, and use in Ending the Epidemic. I outline the problems of data “siloes,” “gaps”, and “velocity” (or lack thereof), which make it difficult to adequately track campaign progress. While data management is often portrayed in the social science literature as a project of state power (Foucault 1978), there certainly are ways in which Ending the Epidemic attempts to democratize knowledge by making it “transparent” and publicly accessible, for example through the EtE Dashboard website. However, as Epstein (1996) points out, even new
knowledge falls on old social ground. As such, knowledge management at the highest levels, even in a well-intentioned campaign like Ending the Epidemic, tends to follow historic patterns of gender, race, and class power. Working around (or through) these dynamics may involve thinking about data categorization in new ways and, as Epstein suggests, requires parallel struggles that challenge “entrenched systems of domination. (Ibid.: 352).

AIDS activists have long engaged with issues related to pharmaceutical access, particularly through fights for access to HIV treatment. In Chapters 4 and 5 I turn to examine the role of pharmaceuticals in Ending the Epidemic by focusing on the power dynamics behind mobilizing Pre-exposure Prophylaxis for HIV (PrEP). In Chapter 4 I argue that PrEP is mobilized largely through marketing techniques that employ an apolitical “activism of awareness” (Gottlieb 2013) targeting MSM of color; an activism that dovetails with pharmaceutical companies’ interests in rolling out more drugs that target the healthy rather than the sick (Dumit 2012). This tactic is problematic for its disproportionate attention to one specific population, not solely because it restricts access to a potentially lifesaving drug, but because that drug is part of an entire health intervention. If Ending the Epidemic’s big goal is actually to end health disparities by getting more people into healthcare, then the campaign is missing a crucial opportunity with PrEP. Some providers suggest that, instead, it is best for them to recommend PrEP to their patients through an informed conversation that opens the patient up to more meaningful engagement in their own healthcare. This is an intervention far beyond simply offering drugs and one that also has potential benefits far beyond the target PrEP populations.

Chapter 5 delves deeper into the politics of mobilizing PrEP by looking at this mobilization through the lens of gender, race, and sexuality. In this chapter, I argue that much of the messaging around PrEP frames it as an intervention that offers sexual freedom and choice.
This is a groundbreaking idea for those whose only option for safe sex has been condoms for the past several decades since AIDS was discovered. However, the language of “choice,” often also associated with a woman’s right to “choose” abortion, is also the language of the free market. In theory, consumers are free to choose whatever product or service best suits them, as long as they can pay. But we in the social sciences know this contention to be untrue, and in fact the free market tends to perpetuate inequity. This same principle seems to hold true in the context of PrEP marketing where, despite a strong focus on some populations that typically have less power in the marketplace (e.g. men of color), inequalities along the lines of race, class, and gender still exclude other populations, like women of color. Perhaps, then, the PrEP project is also about re-opening the door to the sexual freedom of the 1960s and ‘70s, though this freedom is still restricted to those for whom sexual desire has always been socially acceptable.

In sum, Ending the Epidemic organizers have clearly made efforts to re-shape the power dynamics of AIDS activism in this current phase, but they are doing themselves a disservice by: 1) treating this campaign as the actual end of AIDS; and 2) relying too heavily on the authoritative knowledge that has long proven a challenge for the movement to tell them which way the wind is blowing. Indeed, the heavy focus on MSM of color in the campaign comes from statistics (frequently cited) released over the past few years showing that this is the only population experiencing an uptick in HIV incidence. Certainly, this is not a trend to ignore, but this dissertation has argued that social inequalities generally perpetuate themselves along with the longstanding points of blindness that make it more difficult for certain social groups to be “seen” than others. MSM have long been the focus of AIDS activism and therefore more likely to garner attention while other populations, like women, have always had to fight for representation.
If the academic literature on AIDS has taught us one thing it is that resources, including knowledge, are controlled by the powerful, often to the detriment of the less powerful. When I graduated from college 12 years ago, I started working with the Athena Network (http://www.athenanetwork.org/), an organization that advocates for gender equity in the global response to HIV/AIDS. Although my affiliation with the organization has waned over the years, certainly my experiences working with them inspired this dissertation. Through Athena I learned that the most accurate, if not the most influential, knowledge about the epidemic comes from those who are most affected by the inequalities that drive the virus in the first place. This is not necessarily statistical knowledge. It is not necessarily knowledge that is published in policy briefs or academic journals. While EtE does nod to some of this knowledge (e.g. a focus on transgender women of color that some recognize is prompted by “anecdotal” knowledge more than by formal publications), who counts and whose experiences count as evidence for the purposes of the campaign is still circumscribed by race, ethnicity, gender, and class.

If Ending the Epidemic organizers want to be truly successful, they should start thinking through this moment not as a finite end, but rather as an opportunity to look forward. While MSM of color may be highly affected now, the history of HIV/AIDS has taught us that it is a virus we need to anticipate; where will it go next? The research detailed in this dissertation suggests that young people, and particularly young people of color regardless of sexual orientation, are in fact the population that deserves the most attention. Not having grown up in the age of fear around HIV/AIDS, young people today know far less about the virus than those who grew up in the 1980s and ‘90s. They no longer have the healthy fear of their predecessors and thanks to the legacy of the George W. Bush administration, may not have the access to accurate information as well. As evidenced by the disruption a group of young people caused at
the December 2015 World AIDS Day event in Harlem and by the lack of attention paid to Christina at the Summer 2015 implementation kickoff event, it is not clear that young people have been meaningfully engaged in Ending the Epidemic to date. Although age inequality is not something that is addressed much in the anthropological literature on AIDS in the U.S. (although it plays a more prominent role in the literature on AIDS in Africa (e.g. Leclerc-Madlala 2002, Leclerc-Madlala 1997, Gallant and Maticka-Tyndale 2004)) and it is not something I deal with much throughout the dissertation, it is clearly a point to pay attention to.

One way to do this may be through health service providers. Sometimes considered “unusual suspects” among providers who specialize in HIV/AIDS, providers like Dr. Rivera and Dr. Daskalakakis make the case for effective service provision through an empathetic relationship between doctor and patient. Certainly we know that more caring providers encourage patients to access and stay in care (Beach et al. 2006), and if young people are able to stay on their parents’ health insurance longer under the Affordable Care Act, they may be better positioned to stay in care if they have access to quality, informed providers. This makes reaching all providers, not just HIV/AIDS service providers, particularly important for Ending the Epidemic as well.

In addition, the lack of attention to cisgender women in the Ending the Epidemic campaign is notable and worth re-examining. As detailed in Chapter 3, there are grave disparities in HIV infections among women of different racial and ethnic backgrounds, but while disparities between MSM of different races are considered a battle cry, differences among women are not. Although women make up a smaller overall proportion of the epidemic in the U.S., we cannot ignore these disparities within disparities. Women of color already face many uphill battles due to the intersection of their gender and race (and often class). If the goal of ending the epidemic is to end inequality, certainly this is not a population to ignore.
Most importantly, though, as I mentioned in the Introduction, women long went undiagnosed with HIV/AIDS at the beginning of the epidemic due to a lack of evidence around HIV infection in women and how to recognize it. This had implications not only for the epidemic in the U.S., but worldwide. At a time when HIV/AIDS infections among women outnumber men in the region hardest hit by the virus (sub-Saharan African) (UN Women n.d.), we cannot afford to disproportionately generate knowledge about HIV/AIDS (and particularly prevention, as evidenced by the body of evidence around PrEP) that focuses on men. While I would never advocate solely for this kind of knowledge in place of the grassroots knowledge I describe above, the power of scientific knowledge can’t be denied. When that knowledge is generated in the U.S., it travels to other parts of the world, and a lack of authoritative knowledge makes it all the more difficult to design and implement effective policies and programs for those who need them most. Susser (2009) calls a similar phenomenon, in which U.S. political priorities are exported to other continents through global policies such as PEPFAR, “imperial moralities” (45). These moralities, themselves generated by a system in which knowledge about gender inequality is handed down and yet inequality continues to repeat itself (e.g. Rapp 2000; Martin 1987), in turn have the power to shape the health landscape at the global level. So, while Ending the Epidemic focuses on New York State, the state and the research conducted there do not exist in isolation. Given this context, EtE organizers and participants have a responsibility to think more broadly about the implications of their work well beyond the state’s borders.

**Implications for the Field**

This dissertation has implications for those researching social activism, pointing to examples of actual moments in which Ending the Epidemic participants grappled over the politics of representation and inclusion in a social movement, and raising questions around what
it takes to be an activist or an advocate today. Questions of who is meaningfully included in contemporary AIDS activism, why, and how are further complicated by neoliberal politics that shape the conditions in which activism plays out (e.g. the “collaboration” required of health service providers in order to receive state funding). Those who have historically enjoyed little power in the neoliberal marketplace continue to enjoy less power in a large social movement like Ending the Epidemic, but this may be changing and is certainly worth exploring further in other studies. In addition, this dissertation seeks to contribute to the literature on pharmaceuticals by exploring the language of “choice” as it is often used in the literature on reproduction, and its implications for who is ultimately influenced by a campaign like Ending the Epidemic. Finally, analyses of the politics of knowledge and the power of data may have implications for contemporary science and technology studies (STS) and for those examining the expanding role of data management and audit culture in the nonprofit sector (e.g. Merry 2016).

**Directions for Future Research**

This dissertation raises several questions for future research. Since my data collection took place during the initial start-up phase of the Ending the Epidemic campaign and the campaign hadn’t yet been fully rolled out on the ground, it would be worth exploring the campaign in its implementation. Particularly paying attention to the ways in which concerns around race, gender, sexuality and inequality that were raised in the campaign’s planning stages have or have not been addressed on the ground. Now that a transgender advisory committee has been created, for example, what is the role of this committee in the overall implementation of Ending the Epidemic? Where do representatives come from and how much influence do they have with campaign organizers at the AIDS Institute, or even at the level of state government?
Initially, I planned to focus this concluding chapter on efforts to cure AIDS. While I have ultimately shifted my final thoughts away from this theme, this area certainly seems like a fruitful one for future inquiry. While EtE has focused on “ending” the AIDS epidemic through combined efforts around prevention, treatment, and care from the level of state policy down to providers working on the ground, a potential cure presents a different picture of the end of AIDS. Similar to PrEP, I suspect that a cure for AIDS, once it has been developed, will raise similar issues around availability, access, and inequality that we often find in the literature on pharmaceuticals and vaccination.

Further, during the course of my research I attended a couple of different events related to the cure that re-emphasized for me the importance of science and the development and management of scientific knowledge as part of the HIV/AIDS field. During one of these events, a visit to a lab in New Jersey, I was struck by the ways in which science was put on display, through two separate presentations and also through a lab tour in which we were required to wear special protective gear, to legitimize claims that the cure is in sight. At the second event, a symposium held at the University of California, San Francisco, prominent scientists took to the stage to explain complicated diagrams detailing the different possibilities for curing AIDS through first “recording” the HIV reservoir and then taking different steps to eliminate it. AIDS activists were in attendance at both of these events, exemplifying the endurance of gains made around community involvement in the early days of the epidemic. However, the language and trappings of science remained a barrier difficult to cross. Further, the panel consisted entirely of men, all of whom were white except for one. As this new phase of AIDS science matures, how will it play out in terms of access not only to potential treatments, but to the knowledge itself?
How might this compare to fights around access and inclusion that played out in the field decades ago?

Finally, it goes without saying that the findings above suggest a need for more research on HIV prevention in particular among young people and among women. Thinking toward the future of the epidemic, these are two populations that we cannot afford to ignore in New York and beyond. Among young people, it would be useful to evaluate what they know about HIV/AIDS, what concerns them most about their own health, and how they use/seek out healthcare sexual and reproductive health in the context of the Affordable Care Act (which allows children to stay on their parents’ health insurance until the age of 26). Among women, the PrEP research agenda for MSM points to some noticeable gaps in the knowledge base around pharmaceutical prevention options for women, such as determinants of adherence and the effectiveness of event-driven (versus daily) use. Not only have microbicide trials failed due to a lack of understanding around adherence among women, but the research agenda on PrEP should not be driven by assumptions that women are better at taking medication regularly than are men.

**Concluding Thoughts**

As detailed above, when I was in the midst of my research and long before I even began writing this dissertation, I knew what I wanted my conclusion to be about: the cure for AIDS. It seemed that a dissertation about “ending” AIDS through a combination of prevention, treatment, and care should rightfully finish with a discussion of the increasing possibility that we could in fact end AIDS through the discovery of a cure in the near future, and the implications of this finding. So, I visited a lab in New Jersey where the head researcher claims to have developed a certain kind of technology that could cure AIDS. I attended a symposium on the cure at UC San Francisco, where the AIDS Research Institute has received a multi-million dollar grant to find a
cure. I planned to write about the opportunities and challenges that this discovery might have based on what I observed through Ending the Epidemic.

But then Donald Trump was elected President of the United States in November 2016, beating Hillary Clinton (though some would still say Hillary technically won the election), our country’s first female presidential candidate from a major political party. In response, I (Suchman 2016) and others (D’Angelo 2016; Dastagir 2016) published pieces decrying the fact that sexism is still so strong even many women would rather elect an under-qualified man who has openly expressed sexist and racist views (and actions) than elect a woman to presidential office. A slew of articles came out pointing to the class divisions that led to Trump’s election while simultaneously blinding liberal elites to his impending victory (Davis 2017; Stern 2017).

And even before Trump took office, the protest plans began. The Women’s March, planned for January 21, 2017 in Washington DC, only two days after Trump’s inauguration, quickly took on a life of its own. The march ultimately attracted hundreds of thousands of people, possibly close to a million, making it one of the largest ever to take place in the nation’s capital.26 For those who could not be in DC, solidarity marches took place across the globe with major cities like New York, Los Angeles, and London similarly attracting hundreds of thousands of protesters. Some estimates place the total number of protesters worldwide at between two and five million.27 These protests for women’s rights were quickly followed by a series of protests for immigrant rights on the heels of an executive order heavily restricting immigration to the U.S. from several Muslim-majority countries. More massive protests are planned in defense of “science” in April 2017 in response to both statements and policies from the Trump White House.

27 Przybyla and Schouten 2017; www.womensmarch.com
that appear hostile to evidence-based policymaking and particularly to the science behind climate change.  

And just as so many participants in my research noted that New York State has often been at the forefront of progressive change, this moment has been no different. Not only have New Yorkers turned out in large numbers to engage in public protests, but the legislative agenda coming out of the Cuomo administration has been truly impressive. Since Trump’s election in November 2016, Governor Cuomo has passed legislation: improving access to STI testing and to PrEP;  

making state and city university systems free of cost for low- and middle-income students;  

and making New York a “sanctuary state” for immigrants just to name a few. These developments suggest an aggressive liberal agenda coming out of Albany that clearly aims to reduce inequalities in New York State by taking a multi-pronged stance.

If one of the big questions, if not the big question, of this dissertation is whether or not we can achieve intersectionality in a campaign to end AIDS, then all of these actions give me great optimism. As I quoted James Baldwin at the beginning of this chapter, “…nothing can be changed until it is faced.” We are indeed facing attacks on so many types of vulnerabilities from our federal government that the attacks cannot be ignored and we almost have no choice but to respond in kind. Further, popular sentiment around issues of race, class and gender and their intersectionality is changing. Not just in terms of offerings on TV or the number of models of color featured in fashion magazines, but there is a growing awareness of and ability to label whiteness as a unique identity in itself and not just a default setting (see for example Al’s 2014),

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28 http://www.salon.com/2017/02/02/the-march-for-science-is-set-to-happen-on-earth-day_partner/
and white male dominance as problematic (Filipovic 2017). The standards against which all non-white, non-male, non-heterosexual identities are measured are changing.

Like all social activities, protest and political activism happen within a larger social frame and, as such, mirror that frame in terms of power dynamics, even when the explicit goal of the movement is to change those very dynamics. So, if the power dynamics within a movement are ever to change, the society within which that movement operates must change as well. A colleague in the field once told me that society is like a rock and AIDS is like water; when you pour water over the rock, it always finds the cracks. Indeed, we may never really “end” AIDS until all of society’s cracks have been shored up, but if there ever was a moment in which popular sentiment seemed to be turning to recognize exactly what those cracks are and where they come from, this certainly feels like one.
APPENDIX 1: LIST OF ACRONYMS

ACT UP = AIDS Coalition To Unleash Power
AI = New York State Department of Health AIDS Institute
CDC = United States Centers for Disease Control and Prevention
DOHMH = New York City Department of Health and Mental Hygiene
DOH = New York State Department of Health
EtE = Ending the Epidemic
MCDPH = Monroe County Department of Public Health
McPETE = Monroe County Partnering to End the Epidemic
PLHA = People living with HIV/AIDS
TAC = Treatment Action Campaign
UNAIDS = Joint United Nations Programme on AIDS
USAID = United States Agency for International Development
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