

SCIENCE AND SOCIETY, 2022

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COMBATTEZ LE SIDA. REJOIGNEZ ACT UP A LA GAY PRIDE  
RENDEZ-VOUS LE SAMEDI 20 JUIN, PLACE DE LA REPUBLIQUE A 15H00

## LIVING WITH HIV-AIDS

Politics of Knowledge in an Epidemic

A corpus constituted by Gaëtan Thomas

**FORCAST**

Formation par la Cartographie de Controverses à l'analyse des sciences et des techniques



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# 1. Introduction

*Guidelines for the readings :*

- How did activists defined their collective identity, facing scientific and social prejudices? How does the use of drugs shape both the everyday life and social status of users?
- How is lay expertise constituted? How does lay experts and experts interact? Think about the co-production of lay expertise and victims.
- How does the voice of activists shapes the work of scientists? And their socio-political position?
- Are epidemics a mere scientific fact? Which factors could impact the development of an epidemic/pandemic?
- Who defines scientific facts? What is the role of institutions in this definition?
- Could sciences have a political agenda? Could sciences be a tool for political agendas?
- What about the interaction between scientific and political temporalities?

# Global HIV/AIDS Timeline

## Adapted from:

<https://www.kff.org/global-health-policy/timeline/global-hivaids-timeline/>

On June 5, 1981, the U.S. Centers for Disease Control and Prevention (CDC) issued its first warning about a relatively rare form of pneumonia among a small group of young gay men in Los Angeles, which was later determined to be AIDS-related. While scientists believe that HIV was present years before the first case was brought to public attention, 1981 is generally referred to as the beginning of the HIV/AIDS epidemic. Since that time, tens of millions of people have been infected with HIV worldwide. The Global HIV/AIDS Timeline is designed to serve as an ongoing reference tool for the many political, scientific, cultural, and community developments that have occurred over the history of the epidemic.

## 1981

- U.S. Centers for Disease Control and Prevention (CDC) reports first cases of rare pneumonia in young gay men in the [June 5 MMWR](#). These cases were later determined to be AIDS. This marks the official beginning of the HIV/AIDS epidemic. CDC also issues report on highly unusual occurrence of rare skin cancer, Kaposi's Sarcoma, among young gay men in the July 4 MMWR.

## 1982

- U.S. CDC [establishes](#) term Acquired Immune Deficiency Syndrome (AIDS); refers to four "identified risk factors:" male homosexuality, intravenous drug abuse, Haitian origin, and hemophilia A.

- Gay Men's Health Crisis, the first community-based AIDS service provider in the U.S., established in New York City.
- First AIDS case reported in Africa.

## 1983

- People living with AIDS (PWAs) take over plenary stage at a U.S. conference and issue statement on the rights of PWAs referred to as [The Denver Principles](#).

## 1984

- U.S. Department of Health and Human Services (HHS) announces Dr. Robert Gallo of the National Cancer Institute finds that a retrovirus causes AIDS. Dr. Gallo and Dr. Luc Montagnier of the Pasteur Institute hold joint press conference in June announcing discovery that a retrovirus (identified as HTLV-III by Gallo and LAV by Montagnier; see 1983 entry) — later named Human Immunodeficiency Virus (HIV) — causes AIDS.

## 1985

- At least one HIV/AIDS case reported in each region of the world. First HIV case reported in China.
- First HIV test licensed by the U.S. Food and Drug Administration (FDA); detects antibodies to HIV. Blood banks begin screening the U.S. blood supply.

## 1986

- AZT, the first drug used to treat HIV/AIDS, begins clinical trials.

## 1987

- First antiretroviral (ARV) drug — zidovudine or AZT (a nucleoside analog) — approved by U.S. FDA.
- AIDS Coalition to Unleash Power (ACT UP) established in New York in response to

proposed cost of AZT; the price of AZT is subsequently lowered.

#### 1992

- AIDS becomes number one cause of death for U.S. men ages 25 to 44.

#### 1995

- First protease inhibitor, saquinavir, approved in record time by the U.S. FDA, ushering in new era of highly active antiretroviral therapy (HAART).

#### 1996

- 11th International AIDS Conference (“One World, One Hope”) held in Vancouver, Canada; highlights effectiveness of HAART, creating a period of optimism.
- Brazil begins national ARV distribution; first developing country to do so.
- Number of new AIDS cases diagnosed in U.S. declines for first time in history of epidemic.
- HIV no longer leading cause of death for all Americans ages 25-44; remains leading cause of death for African-Americans in this age group.

#### 1998

- Treatment Action Campaign (TAC) forms in South Africa; grassroots movement pushes for access to treatment.

#### 2000

- 13th International AIDS Conference (“Breaking the Silence”) held in Durban, South Africa; first time held in developing nation; heightens awareness of the global pandemic.

#### 2002

- HIV is leading cause of death worldwide among those aged 15-59.

- Global Fund to Fight AIDS, Tuberculosis and Malaria begins operations; approves first round of grants later this year.

#### 2003

- President Bush announces [President's Emergency Plan for AIDS Relief \(PEPFAR\)](#), a five-year, \$15 billion initiative to address HIV/AIDS, TB, and malaria in hard hit countries.

#### 2010

- Large international clinical study ([iPrEx](#)) shows daily dose of combination antiretroviral pill reduced risk of acquiring HIV among men who have sex with men and transgendered women who have sex with men.

#### 2011

- Large multinational study of serodiscordant, mostly heterosexual, couples ([HPTN 052](#)) shows early treatment of HIV-infected person greatly reduces transmission to negative partner.

#### 2012

- U.S. FDA [approves](#) the use of Truvada (emtricitabine/tenofovir disoproxil fumarate) for reducing risk of HIV infection in uninfected individuals at high risk, marking the first HIV treatment to be approved for pre-exposure prophylaxis (PrEP).

#### 2015

- Findings from [Ipergay](#) and [PROUD](#) studies show PrEP to be effective in reducing HIV acquisition among gay men.

### **What Is HIV?**

HIV (human immunodeficiency virus) is a virus that attacks cells that help the body fight infection, making a person more vulnerable to other infections and diseases. It is spread by contact with certain bodily fluids of a person with HIV, most commonly during unprotected sex (sex without a condom or HIV medicine to prevent or treat HIV), or through sharing injection drug equipment.

If left untreated, HIV can lead to the disease AIDS (acquired immunodeficiency syndrome).

The human body can't get rid of HIV and no effective HIV cure exists. So, once you have HIV, you have it for life.

However, by taking HIV medicine (called antiretroviral therapy or ART), people with HIV can live long and healthy lives and [prevent transmitting HIV](#) to their sexual partners. In addition, there are effective methods to prevent getting HIV through sex or drug use, including [pre-exposure prophylaxis \(PrEP\)](#) and [post-exposure prophylaxis \(PEP\)](#).

First identified in 1981, HIV is the cause of one of humanity's deadliest and most persistent epidemics.

### **What Is AIDS?**

AIDS is the late [stage of HIV infection](#) that occurs when the body's immune system is badly damaged because of the virus.

In the U.S., most people with HIV do not develop AIDS because taking HIV medicine every day as prescribed stops the progression of the disease.

A person with HIV is considered to have progressed to AIDS when:

the number of their CD4 cells falls below 200 cells per cubic millimeter of blood (200 cells/mm<sup>3</sup>). (In someone with a healthy immune system, CD4 counts are between 500 and 1,600 cells/mm<sup>3</sup>.) OR

they develop one or more [opportunistic infections](#) regardless of their CD4 count.

Without HIV medicine, people with AIDS typically survive about 3 years. Once someone has a dangerous opportunistic illness, life expectancy without treatment falls to about 1 year. HIV medicine can still help people at this stage of HIV infection, and it can even be lifesaving. But people who start ART soon after they get HIV experience more benefits—that's why HIV testing is so important.

<https://www.hiv.gov/hiv-basics/overview/about-hiv-and-aids/what-are-hiv-and-aids>

## 2. Identity politics and scientific expertise: the AIDS movements in the US, 1980s



## People living with AIDS are no victims

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In : "The Denver Principles," considered the founding statement of AIDS activism, drafted in 1983 at a conference organized in Denver (USA) by a group of people living with AIDS

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We condemn attempts to label us as "victims," which implies defeat, and we are only occasionally "patients," which implies passivity, helplessness, and dependence upon the care of others. We are "people with AIDS."

*We recommend that health care professionals:*

1. Who are gay, come out, especially to their patients who have AIDS.
2. Always clearly identify and discuss the theory they favor as to the cause of AIDS, since this bias affects the treatment and advice they give.
3. Get in touch with their feelings (fears, anxieties, hopes, etc.) about AIDS, and not simply deal with AIDS intellectually.
4. Take a thorough personal inventory and identify and examine their own agendas around AIDS.
5. Treat people with AIDS as whole people and address psychosocial issues as well as biophysical ones.
6. Address the question of sexuality in people with AIDS specifically, sensitively, and with information about gay male sexuality in general and the sexuality of people with AIDS in particular.

*We recommend that all people:*

1. Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us, separate us from our loved ones, our community, or our peers, since there is no evidence that AIDS can be spread by casual social contact.
2. Do not scapegoat people with AIDS, blame us for the epidemic, or generalize about our lifestyles.

*We recommend that people with AIDS:*

1. Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda, and to plan their own strategies.
2. Be involved at every level of AIDS decision-making and specifically serve on the boards of directors of provider organizations.
3. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.
4. Substitute low risk sexual behaviors for those that could endanger themselves or their partners, and we feel that people with AIDS have an ethical responsibility to inform their potential sexual partners of their health status.

*People with AIDS have the right:*

1. To as full and satisfying sexual and emotional lives as anyone else.

2. To quality medical treatment and quality social service provision, without discrimination of any form, including sexual orientation, gender, diagnosis, economic status, age, or race.
3. To full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment, and to make informed decisions about their lives.
4. To privacy, to confidentiality of medical records, to human respect, and to choose who their significant others are.
5. To die and to *live* in dignity.

## ACT UP: A Short History

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In: Gould Deborah (2009), *Moving Politics. Emotions and ACT UP's fight against AIDS*, Chicago, The University of Chicago Press: 4-5.

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Arguing that confrontational direct action was needed to fight the exploding AIDS crisis, oppositional AIDS activist groups began to emerge in 1986–87 out of lesbian and gay communities around the United States. With cumulative deaths from AIDS-related complications nearing and soon surpassing twenty thousand nationally — the vast majority of them gay and bisexual men — lesbians and gay men formed direct-action AIDS groups in San Francisco (Citizens for Medical Justice [CMJ]), New York (the Lavender Hill Mob), and Chicago (Dykes and Gay Men Against Repression/Racism/Reagan/the Right Wing [DAGMAR]). ACT UP (AIDS Coalition to Unleash Power) formed in New York City in March 1987, and other chapters soon sprouted up across the country, quickly forming a national direct action AIDS movement. Over the course of its life there were more than eighty ACT UP chapters in the United States and more than thirty internationally. Through raucous demonstrations, acts of civil disobedience, zaps and disruptions, die-ins and other forms of street theater, meetings with government and other officials, and eye-catching agitprop, ACT UP and similar direct-action AIDS groups intervened in every aspect of the AIDS epidemic, with tremendous effect. The movement's profound impact on the course of the epidemic is evident in the long list of victories it secured (sometimes working alone, sometimes in coalition). ACT UP forced the Food and Drug Administration (FDA) to speed up the drug-approval process and to adopt policies that allowed people with life-threatening illnesses access to experimental drugs prior to approval. The movement's efforts reconfigured scientific procedures, and thus scientific research itself, by securing the inclusion of people with HIV/AIDS in government and corporate AIDS decision-making bodies, allowing affected populations to have input into drug trial design and other aspects of drug research. ACT UP pushed the Centers for Disease Control (CDC) to expand the definition of AIDS to include infections and diseases commonly occurring in HIV-infected women and poor people. Direct-action AIDS activists succeeded in attracting greater attention to the needs of multiple populations with AIDS, including women and people of color, and won more funding for AIDS research, social services, and safe-sex education. ACT UP forced pharmaceutical companies to lower the prices of AIDS drugs; prodded insurance companies to reimburse for non-FDA approved, experimental drugs; pushed government bodies to create needle-exchange programs; and prevented the passage of extremely repressive AIDS legislation. Direct-action AIDS activists also altered public perceptions of people with AIDS (PWAs)—a less quantifiable result that nonetheless had life and-death consequences.

In addition to the many crucial victories that prolonged and saved lives, ACT UP's interventions posed a powerful challenge to conventional understandings of homosexuality and of sexuality more broadly. Indeed, ACT UP gave birth to a new queer generation that shook up straight and gay establishments with defiant, sex-radical politics. By reeroticizing and revalorizing all kinds of sex, ACT UP queers furnished a strong response to the sex-negative early years of the AIDS crisis. In many ways, ACT UP could be credited as well with the birth and explosion of queer theory in the academy; during the ACT UP years the separation between the streets and the academy was less pronounced than in other periods, and learning happened across these more typically segregated worlds. ACT UP also brought a renewed militancy to lesbian and gay

activism— unsettling “business as usual” in both straight and gay worlds. Demonstrating, literally, the efficacy of confrontational direct action politics, ACT UP blew open political horizons that previously had extended only to voting, lobbying, and the occasional national demonstration or protest march. ACT UP queers opened up ways of being gay and of being political that had been foreclosed by the more mainstream oriented lesbian and gay establishment, paving the way for new identity and political formations among sexual and gender outlaws of all ages. In addition to influencing lesbian and gay politics, ACT UP also affected subsequent activists, particularly those in the alternative globalization movement, many of whom were inspired by ACT UP’s theatrical, direct-action tactics and sleek, agit-prop style.

# Achieving Scientific Credibility

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In: Epstein Steven (1995), "The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials" *Science, Technology, & Human Values*, 21, n. 4: 411-426

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## The Rise of the AIDS Movement

[...] Central to the self-understanding of such movements is a focus on the values of autonomy and identity. Yet as Cohen argues, the salient feature of the new social movements is not so much that they assert identities – something all movements do – but that the participants have become reflexively aware of their own active involvement in contested processes of identity construction. [...] This emphasis on identity politics has, in certain crucial respects, facilitated the capacity of AIDS activists to engage with scientific knowledge production. As Wynne has noted, "the unacknowledged reflexive capability of laypeople in articulating responses to scientific expertise" is crucially dependent on their construction and renegotiation of a social identity. Furthermore, because identity politics are preoccupied with non material issues – with questions of representation and meaning – its practitioners are inclined to wage struggles over the definition of reality. And precisely because identity politics stand in opposition to what Foucault has called "normalization"; such movements are highly sensitive to the imposition of norms, categories, and interpretations by outside authorities. Understanding AIDS activism as a new social movement helps explain why these activists might have a greater inclination and capacity to participate in the construction of social meanings, including forms of knowledge.

The AIDS movement is broad based and diverse, ranging from grass roots activists and advocacy organizations to health educators, journalists, writers, service providers, people with AIDS or HIV infection, and other members of the affected communities. [...] [It] is the first social movement in the United States to accomplish the mass conversion of disease "victims" into activist-experts, and in that sense the AIDS movement stands alone, even as it begins to serve as a model for others. Its distinctive approach toward scientific and medical questions owes to a specific constellation of historical and social factors.

To some extent, the unique features of the clinical picture of AIDS have shaped the development of an activist response. AIDS and HIV have affected many young people in their twenties and thirties – a group for which there is little social expectation that they will passively await death. Indeed, those who test positive on HIV antibody tests (available since 1985) are likely to be told by medical authorities to expect some number of years of outwardly normal health before the onset of symptoms. During this period, activism not only is feasible from a physical standpoint, but seems eminently practical from a political and psychological standpoint. Even more fundamentally, the distinctive social epidemiology of AIDS has shaped the character of the public engagement with science. From the start and up to the present day, AIDS has been understood, both in epidemiological and lay parlance, as a disease of certain already-constituted social groups distinguished by their lifestyle, their social location, or both. As a result, the very meaning of AIDS is bound up with the cultural understandings of what such groups are like, while the very identity of the groups

is shaped by the perception of them as “the sort of people who get this illness.” If AIDS were not deadly, if it were not associated with taboo topics such as sex and drug use, and if the groups affected were not already stigmatized on other counts, such linkages between identity and illness might be of little consequence. As it is, the AIDS epidemic has engendered fear and prejudice and has sparked the necessity, on a mass scale, for what Goffman once called “the management of spoiled identity.”

Gay men, the group whose identity has been shaped most thoroughly by the confrontation and association with the epidemic, entered the era of AIDS equipped with a whole set of crucial resources to engage in the struggle over social meanings. In the recent past, gays and lesbians in the United States had achieved a singular redefinition in social status, challenging the dominant frames of homosexuality as illness or immorality and reconstituting them-selves as a legitimate “interest group”; pursuing civil rights and civil liberties. With the limited successes of the “homophile” movement of the 1950s and 1960s and the more substantial impact of the gay liberation movement of the 1970s, gay men and lesbians recasted social norms, constructed organizations and institutions, and established substantial and internally differentiated subcultures in urban centers throughout the United States.

By the time the AIDS epidemic was recognized in 1981, the gay movement was thoroughly engaged in projects of identity politics that linked tangible political goals to the elaboration and assertion of an affirmative group identity. A threat to identity, therefore, was a threat that the movement could easily understand-and one against which it was quick to mobilize. Negotiation with the medical profession was not entirely foreign to this movement because a specific component of the gay liberation agenda had been “demedicalization” of gay identity. Indeed, gay activists had long been inclined to view medical authorities with some suspicion. Furthermore, many lesbians (and heterosexual women) who would become active in the AIDS movement were schooled in the tenets of the feminist health movement of the 1970s, which also advocated skepticism toward medical claims and insisted on the patient’s decision-making autonomy.

The AIDS movement, in other words, was built on the foundation of the gay and lesbian movement and borrowed from its particular strengths and inclinations. It mattered that gay communities had pre-existing organizations that could mobilize to meet a new threat, and it mattered that these communities contained (and in fact were dominated by) white, middle-class men with a degree of political clout and fund-raising capacity unusual for an oppressed group. It was crucially important, as well, that gay communities possessed relatively high degrees of “cultural capital” – cultivated dispositions for appropriating knowledge and culture. These communities contain many people who are themselves doctors, scientists, educators, nurses, professionals, or intellectuals of other varieties. On the one hand, this cultural capital has provided the AIDS movement with an unusual capacity to contest the mainstream experts on their own ground. On the other hand, it facilitates mediation and communication between “experts” and “the public.”

### **AIDS Treatment Activism**

The U.S. AIDS movement encompasses a wide range of grass-roots activists, lobbying groups, service providers, and community-based organizations; represents the diverse interests of people of various races, ethnicities, genders, sexual preferences, and HIV “risk behaviors”; and has engaged in a variety of projects directed at numerous social institutions. Treatment activism, more narrowly defined, is the province of

particular movement organizations. It includes specific subcommittees of ACT UP – the AIDS Coalition to Unleash Power – including the Treatment & Data Committee of ACT UP/New York (along with a more recent spin-off organization called the Treatment Action Group) and the Treatment Issues Committee of ACT UP/Golden Gate in San Francisco. Another key player is the San Francisco-based organization Project Inform, which lobbies for the development of effective AIDS treatments and works to educate laypeople, particularly in gay communities, about treatments. In addition, a number of independent publications, including the San Francisco-based *AIDS Treatment News* and the New York-based *Treatment Issues* (published by Gay Men's Health Crisis), have played a crucial role in evaluating clinical research and providing information about clinical trials that is considered widely credible and often relied on by doctors as well as patients.

AIDS treatment activism dates to the mid-1980s, when activists began clamoring for the rapid approval of experimental treatments and established so-called “buyers clubs” organizations occupying a gray zone of legality that imported and distributed unproven treatments to patients around the United States. Activist ire was directed largely at the FDA, whose “paternalistic” policies of drug regulation were perceived to rob patients of the right to assume the risk of an experimental treatment. By the late 1980s, however, activist attention had shifted to earlier stages in the drug development pipeline, in part because of growing concerns about the ethics of clinical research and in part because activists recognized that it was no good fighting for faster approval of drugs if there were few such drugs to be approved. This realization implied a shift in targets from the FDA to the NIH and, specifically, to the AIDS Clinical Trials Group of the National Institute of Allergy and Infectious Diseases, the bureaucratic entity responsible for administering the network of publicly funded clinical trials of AIDS treatments. [...]

### **Credibility Tactics**

As Shapin has noted in an analysis of the historical constitution of the expert/lay divide, the question of who possesses cultural competence is “one of the most obvious means by which we, and people in the past, discriminate between ‘science’ and ‘the public.’” The most crucial avenue pursued by treatment activists in the construction of their scientific credibility has been precisely the acquisition of such competence by learning the language and culture of medical science. Through a wide variety of methods – including attending scientific conferences, scrutinizing research protocols, and learning from sympathetic professionals both inside and outside the movement – the core treatment activists have gained a working knowledge of the medical vocabulary. While activists have also insisted on the need to bring “nonscientific” language and judgments into their encounters with researchers, they have nonetheless assumed that the capacity to speak the language of the journal article and the conference hall is a *sine qua non* of their effective participation.

In a learning approach that one such activist characterizes frankly as “ass backwards,” activists often begin with the examination of a specific research protocol in which patients have been asked to participate and, from there, go on to educate themselves about the mechanism of drug action, the relevant “basic science” knowledge base (such as considerations of the viral replication cycle of HIV or the immune pathogenesis of AIDS), and the inner workings of “the system” of drug testing and regulation including the roles of the pharmaceutical companies and the relevant government advisory committees. Although activists have benefited from the presence of a few medical and scientific professionals within their ranks, typically the leading lights of the treatment activist movement have been autodidacts who began as science

novices but came from positions of relative social advantage. Like most of their scientific interlocutors, they have tended – by and large, although by no means exclusively – to be white, middle-class, well-educated men. And in the course of learning truly impressive amounts of technical information about virology, immunology, molecular biology, and biostatistics, they have also been able to parlay their other social and personal advantages into new types of credibility. [...]

[I]ndeed, the remarkable fact is that once they acquired a certain basic familiarity with the language of biomedicine, activists found they could also get in the doors of the institutions of biomedicine. Once they could converse comfortably about viral assays and reverse transcription and cytokine regulation and epitope mapping, activists increasingly discovered that researchers felt compelled, by their own norms of discourse and behavior, to consider activist arguments on their merits. Not that activists are always welcome at the table. [...]

Anthony Fauci, director of the National Institute of Allergy and Infectious Diseases, makes clear that “there are some [activists] who have no idea what the hell they’re talking about,” but he is nonetheless happy to grant that “there are some that are brilliant, and even more so than some of the scientists”. Prominent academic researchers also typically acknowledge the acquisition of scientific competence on the part of key activists. “Mark Harrington is a perfect example,” recalled Douglas Richman, a virologist and member of the AIDS Clinical Trials Group at the University of California, San Diego. “In the first meeting, he got up and gave a lecture on CMV [cytomegalovirus] to us that I would have punished a medical student for in terms of its accuracy and everything else, and he’s now become a very sophisticated important contributor to the whole process”.

A second way in which AIDS treatment activists have striven to present themselves as credible is through the establishment of themselves as representatives. That is, a basic “credibility achievement” of treatment activists has been their capacity to present themselves as the legitimate, organized voice of people with AIDS or HIV infection (or, more specifically, the current or potential clinical trial subject population). This point is easily missed but is important because the three groups-activists, people with AIDS or HIV, and clinical trial participants-overlap but are not isomorphic, and it is a complicated question whether in fact activists do meaningfully represent the diverse groups in the United States that are affected by HIV.

Over time, treatment activism has become more demographically diverse, in part through the mechanism of the Community Constituency Group (the formal organization of activists elected to sit on the committees of the AIDS Clinical Trials Group), the membership of which is mandated by the NIH to represent all the communities affected by HIV. Nevertheless, gay men continue to play the dominant role. Even within gay communities, the question of representation can be complex, in part because the activists are often more politically radical than the gay mainstream on whose behalf they speak and in part because gay researchers and health professionals may also make plausible claims to representation. “What right do these people have to think that they are representing the gay community when I’m also here and just on the other side of the fence”; a prominent gay researcher complained.

Looking back at her experience with treatment activism, one activist who is now completing medical school reflected, “I *never* represented people with AIDS. I represented activists. And those are different



people, you know. They are a subset of people with AIDS". Yet the extraordinary success of treatment activists (who have always been a relatively small group and whose ranks have been further depleted by burnout, illness, and death over the years) stemmed in large part from their capacity to convince the biomedical establishment not only that they spoke for the larger body of patients, but also that they could mobilize hundreds or thousands of angry demonstrators to give muscle to their specific requests. And once activists monopolized the capacity to say "what patients wanted," researchers could be forced to deal with them to ensure that research subjects would both enroll in their trials in sufficient numbers and comply with the study protocols. On the basis of their credibility, activists thus constructed themselves as an "obligatory passage point" standing between the researchers and the trials they sought to conduct. Of course, by the same token, the activists wanted to see the trials conducted; so the point, really, is that the relationship became a powerfully symbiotic one.

A third credibility tactic employed by treatment activists consisted of yoking together methodological (or epistemological) arguments and moral (or political) arguments so as to monopolize different forms of credibility in different domains. A good example was the activist insistence that clinical trial populations should be more fully representative of the different social groups affected by the epidemic. In AIDS trials, as elsewhere, the subject populations early on tended to consist largely of middle-class white men. AIDS activists argued that people from all affected populations – injection drug users and people with hemophilia, women and men, whites and minorities, heterosexuals and homosexuals – must be given access to trials.

One impetus here was the notion (which was itself somewhat new and controversial) that access to experimental treatments was a social good that must be distributed equitably. Most debates about the ethics of clinical trials in the United States in the last quarter century have focused on issues of informed consent and the right of the human subject to be protected from undue risk. AIDS activism has shifted the discourse to emphasize the right of the human subject to assume the risks inherent in testing therapies of unknown benefit and, indeed, to become a full-fledged partner in the experimental process. [...]

A final credibility technique is the taking of sides in pre-existing debates over how clinical research should be done. That is, many of the positions taken by treatment activists are not arguments that they dreamed up; rather, activists have seized on pre-existing lines of cleavage within the biomedical mainstream. I illustrate this point with a brief analysis of how activists promoted "pragmatic" approach to clinical trials in reaction to researchers' insistence on the need to perform "fastidious" trials to generate clean data.

For most clinical researchers, the best way to obtain clean results about drug efficacy was to perform randomized, controlled, clinical trials according to carefully delineated methodological precepts. Activists supported the goals of this research but also recognized that one primary motivation of the actual research subjects was access to otherwise unobtainable and potentially helpful therapies. The perception of activists was that, in the name of clean data, people with lab test values or demographic characteristics outside of a specified range, or those who were currently taking other medications or had taken them in the past, were finding themselves excluded from study protocols. Similarly, those enrolled in studies who took other medications without explicit permission were sometimes threatened with expulsion. The practical effect, activists argued, was that in some cases trials were unable to recruit subjects because the treatment options that were offered were too unattractive. In other cases, people were lying in order to get into trials of

potentially helpful therapies or were cheating on the protocols while trials were under way. That is, in the context of a life-threatening illness among a savvy group of patients, the very emphasis on clean data was itself helping to produce some decidedly messy clinical trials.

Terry Sutton was an activist who wanted to be a research subject in a trial of a drug that he believed might keep him from going blind from cytomegalovirus retinitis (a common opportunistic infection in people with AIDS). Sutton was considered ineligible for participation because he had previously taken another drug for the same condition and the research protocol excluded such patients out of concern with statistical bias. Sutton was quoted in the gay press in 1989, shortly before his death:

“The idea of clean data terrifies me, because it punishes people for trying to treat early. My roommate... has made the decision not to treat early because of the pure subject rule. What he says is “I want to be a pure subject so that I can get access to the best protocol once it starts to move” You only get to be a pure subject once.”

[...] Treatment activists then pushed the critique of fastidious trials even further to raise questions suggested by Terry Sutton’s comment. Did “clean” data come only from “pure” subjects? Was “messy”, “impure” science necessarily worse science? As one prominent treatment activist told a Senate health subcommittee, people with AIDS are not in awe of that “strange and abstract god, clean data”. Similarly, James argued that “good science, like God, patriotism, and the flag, are rhetorical devices designed to be impossible to argue against—devices often used in the absence of a good case on the merits.” Academic researchers could be counted on to come up with “elegant” research designs, but were these the ones that would answer the burning questions most effectively? The metaphors of cleanliness, elegance, and so on varied from the realm of hygiene to that of social status, but the implication in each case was similar: the defense of science put forward by mainstream researchers was an ideology designed to promote the kind of science they happened to do as the only kind that could be called science. [...]

In the end, it has remained somewhat unclear precisely what kinds of science activists would like to see practiced. Are AIDS activists really just trying to “clean up” science by eliminating “biases” that the academic researchers are introducing? Or are they trying to supplant “clean science” with something that answers to different epistemological and ethical aspirations? It may be the tension between these conflicting and ambiguously defined goals, more than anything else, that characterizes the AIDS activists’ engagement with the science of clinical trials. Certainly, activists have rejected a narrow positivist conception of the clinical trial as a laboratory experiment pure and simple. Neither have they endorsed a fully relativist approach to clinical trials, as some SSK analysts have done. For example, in her absorbing analysis of the controversy between Linus Pauling and more orthodox researchers over whether Vitamin C can help cancer patients, Richards argues against “the myth of the ‘definitive’ clinical trial and the neutral evaluation it supposedly entails,” which serves the primary interest of professional legitimization. Rather than worship this false god, Richards suggests, we might be better off abandoning the formal apparatus of the randomized clinical trial, choosing instead “to learn to live with the reality of uncertainty” and to introduce political, ethical, and subjective criteria into the evaluation of treatments. This “implies a more prominent role for nonexperts, for patients and the public at large, in the processes of assessment and decision making”. Quite similarly, AIDS activists have emphasized the artifactual and historical character of the clinical trials methodology, and they have placed a spotlight on the perceptions of the patient as a genuine participant in

clinical research and not just the object of study. Yet, perhaps as they have become more enculturated into the biomedical research process, most AIDS treatment activists share with doctors and researchers a profound investment in the belief that the truth is, in principle, knowable through some application of the scientific method. Although many in the AIDS movement have, at particular moments, argued in favor of tolerating uncertainty as the necessary trade-off for access to experimental drugs, in the end, few activists, and perhaps few people with AIDS or HIV infection, are fully sanguine about the prospect of “[living] with the reality of uncertainty.” This is not surprising because activists, and people with AIDS and HIV, are confronted daily by a burning need to know whether given treatments “work” or not, and such need does not typically take comfort in relativism. The activist critique of the randomized clinical trial unseats that methodology from the pinnacle on which it is sometimes placed, but it also assumes a greater role for such trials than analysts such as Richards would recommend.”

### 3. Fighting AIDS, fighting denial: South Africa in the early 2000s

# The social history of a virus

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In : Didier Fassin and Helen Schneider (2003) "The politics of AIDS in South Africa: beyond the controversies," *British Medical Journal*, 327,7412: 495-

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At the beginning of 2000 [*the President of South Africa*] Thabo Mbeki sent a letter to world leaders expressing his doubt that HIV was the exclusive cause of AIDS and arguing for a consideration of socioeconomic causes. He subsequently invited scientists who shared his view to sit with orthodox experts on AIDS on a presidential panel to advise him on appropriate responses to the epidemic in South Africa. Until April 2002, when Mbeki formally distanced himself from the AIDS "dissidents," the international scientific community's interest in South African policies on AIDS was almost exclusively focused on the polemic raised by the president. His statements questioning the AIDS statistics, on poverty as a cause of immune deficiency, and on the dangers of antiretrovirals, together with government stalling on the roll out of nevirapine to prevent transmission of HIV from pregnant mothers to their babies, dominated the debate.

However, the July 2002 Constitutional Court judgment ordering the government to make nevirapine universally available to pregnant women infected with HIV, followed in October by a cabinet statement supporting wider access to antiretrovirals, may have finally ushered in a new era. It should now be possible to discuss the reality of AIDS in South Africa without reducing the argument to simple dualisms (such as being for or against a viral cause of AIDS, for or against the president). We propose an approach to discussing AIDS in South Africa that is rooted in political economy and political anthropology. Such an approach will shed light not only on the objective determinants of the epidemic, especially social inequalities, but also on subjective responses, such as those of Mbeki.

## **Causes and processes: the political economy of AIDS**

With an estimated five million people infected, South Africa has the highest number of people with HIV in the world. The most striking epidemiological fact is the extremely rapid growth in HIV seroprevalence, for example from 0.7% in pregnant women in 1990 to 24.5% in 2000, reaching 36.2 % in KwaZulu Natal. The impact on adult mortality has been dramatic. In 2000 AIDS accounted for 25% of all deaths, and mortality was 3.5 times higher than in 1985 among 25-29 year old women and two times higher among 30-39 year old men. This rapid evolution, unprecedented even on the African continent, is often seen as yet another symptom of South African "exceptionalism," a phenomenon often referred to in the social sciences.

Yet one need not look far—whether historically or in other countries—to appreciate that social conditions are important in determining exposure to disease. Had a coherent social epidemiology of HIV been more prominent in the scientific arena, rather than the dominant biomedical and behavioural approach, Mbeki might have found interesting alternatives to the explanations of the epidemic given on the dissidents' websites.

Three social factors seem to place South Africa at a higher risk of HIV. Firstly, social inequalities in income and employment status are powerful predictors of HIV infection—although, interestingly, the correlation is

neither linear nor unequivocal. Several factors are involved in the association. A low income or level of employment is associated with:

- A greater exposure to risky sexual experiences
- Diminished access to health information and to prevention
- Higher frequency of sexually transmitted infections generally
- Absent or delayed diagnosis and treatment, and
- Less concern about one's health and the future, because of the harshness of the present.

Secondly, mobility is a well known determinant of epidemics, but in South Africa the situation is particularly complex. Mass resettlements of populations under apartheid, seasonal labour migrations, movements along major trade routes, refugees fleeing war in other parts of Africa, and, since 1990, return of political exiles and liberation armies have all contributed to the spread of infections. Thirdly, sexual violence—whether by known or unknown perpetrators, in commercial or conjugal sex—facilitates viral transmission. Sexual violence is linked with common forms of social and political violence that have long been part of the everyday life of townships and inner city areas. The combination of the three factors can be seen in the practice of “survival sex,” whereby young women in the townships, often migrants from impoverished rural areas, use their bodies as an ordinary economic resource outside the context of prostitution but within the culture of male violence.

Inequality, mobility, and violence are partly the legacy of centuries of colonial exploitation and racial segregation, culminating in the institution of apartheid in the second half of the 20th century. Epidemiologically this segregation translates as differential HIV seroprevalence between black and white groups and between social classes. The case of the mining industry illustrates this legacy. The extraction of a black male labour force from the villages to work the mines has been the motor of the South African economy since the end of the 19th century. These men are accommodated in barracks or hostels, far from their spouses, and commercial sex and access to alcohol are more or less institutionalised social activities in hostel compounds. This social situation explains why educational programmes have had little success in fostering preventive practices, such as condom use. Furthermore, environments where men far outnumber women seem to create explosive conditions for the spread of HIV. In the mining town of Carletonville, even adults with a single lifetime sexual partner face an extraordinarily high prevalence of HIV. In this instance, social context has a far greater bearing on risk of infection than individual sexual behaviour.

### **Suspicion and denial: towards a political anthropology of AIDS**

A political economy of HIV/AIDS falls short, however, of explaining the suspicion in South Africa of science and orthodoxy—a suspicion that is widespread and not confined to the president and his advisers. Examining objective social causes does not preclude an understanding of the politics of AIDS as a subjective phenomenon. A political anthropology may make some sense of what is often presented as merely irrational.

The global controversy created by the president was preceded by several local controversies involving the government. In 1996 the government was accused of wasting public money on a musical show that was supposed to spread the message of prevention. In 1997 it was criticised for officially supporting a treatment,

Virodene, that was later identified as an industrial solvent with no benefit. And from 1998 it was denounced for blocking the use of antiretroviral drugs, which the government justified by citing the drugs' side effects.

In all these arguments, as well as in the virus versus poverty controversy from 2000, two closely linked features appear. The first is the racialisation of the issues, with the government accusing its opponents, whether activists or politicians, of racism. The second is the theme of conspiracy against Africans, either from the country's white conservatives or from the pharmaceutical industry. Both features combine in the somewhat contradictory notion that the AIDS epidemic and its treatments are part of a plot to eradicate the black population.

In South Africa racialisation and conspiracy are rooted in history, and the realm of public health is not exempt from their effects. Epidemics have often been used to enforce racial segregation. The bubonic plague of 1900 in Capetown was used to justify the mass removal of Africans from their homes to the first “native locations” under the first segregationist law, passed in 1883 and called, significantly, the Public Health Act. When AIDS appeared in South Africa it was immediately interpreted in racist terms: some white leaders evoked a supposed African “promiscuity;” they denounced the danger that infected black people posed to the nation; and they even publicly rejoiced over the possible elimination of black people by the disease, as one member of parliament did in 1992. As has recently been shown, in the last years of apartheid government laboratories were developing chemical and biological weapons (including anthrax, intended to eliminate black leaders), were researching contraceptive methods to induce sterility in the African population, and were allegedly attempting to spread HIV through a network of infected prostitutes.

So, what could be seen elsewhere as unfounded suspicion was in South Africa plain reality, historically attested. Remarkably overlooked for purposes of national reconciliation, this history still remains deeply present to many South Africans and explains much of the mistrust towards Western science, medicine, and public health.

An understandable defiance is thus an important element of what is usually termed denial. In fact, denial—a common response among people facing an intolerable situation—has two facets. One is a denial of reality: a reaction that something can't be true, that it is not possible. The other is a denial of the unacceptable: a reaction that something is not normal, that although it exists it should not. Both facets are involved in the denial of the reality of HIV/AIDS. It is difficult for anybody—even a state leader—to fully comprehend the magnitude of the epidemic and its demographic consequences, such as the loss of 20 years of life expectancy within two decades. Also, it is seen as morally unacceptable that a plague can affect the population so massively and so unequally precisely at the point when democracy has at last been achieved—in what seems a remorseless prolongation of the suffering of the weakest people in society.

## The dissent science of nationalism

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In: Robin Stevens (2005) "AIDS, science and citizenship after apartheid," in Leach Melissa, Scoones Ian and Wynne Brian eds. *Science and citizens. Globalization and the challenge of engagement*, London, Zed books: 112-127

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[...] It was only in the late 1980s that AIDS in South Africa began to be acknowledged as a serious public health problem. Prior to this it was widely perceived to be a North American 'gay disease', with San Francisco and New York at its epicentre. It took almost a decade for the seriousness of the AIDS pandemic to filter into the consciousness of South African citizens, the media and policy-makers. By the time of the World AIDS Conference in Durban in July 2000, most South Africans were aware that the country was in the midst of an epidemic of catastrophic proportions.

The 2000 Durban conference also exposed the international AIDS community to the deep rift between mainstream AIDS scientists and government supporters of the AIDS dissidents. Versions of the dissident view were articulated by President Mbeki and senior African National Congress party (ANC) figures such as the late Parks Mankahlana and Peter Mokaba. In a press statement reported in the *Mail and Guardian* newspaper (19 April 2002) a few months before his death, allegedly from AIDS, Mokaba, the then ANC chief electoral officer, presented the AIDS dissident position in the following terms: 'The story that HIV causes AIDS is being promoted through lies, pseudo-science, violence, terrorism and deception ... We are urged to abandon science and adopt the religion of superstition that HIV exists and that it causes AIDS. We refuse to be agents for using our people as guinea pigs and have a responsibility to defeat the intended genocide and dehumanisation of the African family and society'.

This line of argument, which was elaborated in detail by South African and international dissidents, was mercilessly challenged and lampooned by cartoonists and journalists. Its critics also included academics, opposition parties, AIDS activists and health professionals. Yet despite considerable opposition to the dissident view, even within the ruling party, it nonetheless came to represent the official government position on AIDS. This culminated in President Mbeki's establishment of the President's Select Advisory Panel of AIDS experts, comprising an equal weighting of 'establishment scientists' and AIDS dissidents.

In March 2002, a controversial AIDS dissident document was posted on the ANC website. The full title of the document was Castro Hlongwane, Caravans, Cats, Geese, Foot & Mouth and Statistics: HIV/AIDS and the Struggle for the Humanisation of the African. The document was subjected to intense criticism and ridicule from AIDS activists and the media, who portrayed it as an endorsement of President Mbeki's eccentric AIDS 'dissident' views. The document quoted numerous scientific studies and journalistic forays questioning 'mainstream' AIDS science. Throughout, the author(s) referred to the 'omnipotent apparatus' that sought to bring about the dehumanization of the African family and humiliate 'our people' (i.e. Africans). Citing numerous newspaper articles and scientific findings, the document blamed AIDS drugs and pharmaceutical companies for the 'medicalisation of poverty' and for systematically destroying the immune systems of Africans. The document also claimed that 'for the omnipotent apparatus [which includes the media, the



medical establishment and drug companies] the most important thing is the marketing of the anti-retroviral drugs'. It concluded with the following statement:

No longer will the Africans accept as the unalterable truth that they are a dependent people that emanates from and inhabits a continent shrouded in a terrible darkness of destructive superstition, driven and sustained by ignorance, hunger and underdevelopment, and that is victim to a self-inflicted 'disease' called HIV/AIDS. For centuries we have carried the burden of the crimes and falsities of 'scientific' Eurocentrism, its dogmas imposed upon our being as brands of a definitive, 'universal' truth. Against this, we have, in struggle, made the statement to which we will remain loyal – that we are human and African!

Although the ANC attempted officially to distance itself from the document in response to fierce criticism from AIDS activists, the media and health professionals, it became evident that the document's focus on the legacies of colonialism, 'underdevelopment', poverty, the Eurocentrism of science and racist representations of Africans as a 'diseased Other' appealed to a small group of African nationalists within the ANC leadership. Castro Hlongwane reads as an African nationalist defence of the AIDS dissident position in the face of what its authors claimed was a racist representation of AIDS as a 'black disease' associated with sexual promiscuity and the inability of Africans to control their sexual appetites.

More generally, racist narratives about the sexually promiscuous, pathological and uncontrolled black African fuelled Mokaba and Mbeki's African nationalist response. This may help explain support for their dissident ideas. Just as the dissident view attributed AIDS to African poverty and disease engendered by Western racism, colonial conquest, capitalism and underdevelopment, it also challenged attempts to attribute the African AIDS pandemic to 'dysfunctional' sexualities and family structures.

### **Rhetoric, rights and relativism: a case of mixed messages and mixed genres**

Following two years of confused mixed messages, in 2002 President Mbeki began to distance himself from the dissidents, claiming that public perception of the government's support for the dissidents reflected a 'failure of communication on our side' (Cape Times, 25 April 2002). But was this simply 'a failure of communication'? [...]

While AIDS activists and the media described the positions of Mbeki and Mokaba as irrational, politically motivated and incompatible with Western science, it would appear that the dissidents were insisting on their democratic right to critique the science establishment. They did this by drawing attention to the alternative science of the dissidents. ANC spokespersons attempted to justify this high-level government intervention by referring to it as an expression of freedom of thought, a matter of rights. They described Mbeki as a latter-day Galileo, burned at the stake by the media for refusing to conform to scientific orthodoxy. Calls for Mbeki to withdraw from the debate were described as attempts by the 'scientific guild' to shut down and stifle debate on questionable scientific findings. Mbeki's spokespersons also described his interventions as an attempt to 'open up' what was perceived to be a narrowly technical, biomedical framing of the AIDS pandemic which ignored conditions of poverty and underdevelopment. Whereas much of this critique of the biomedical paradigm would have sat comfortably with most left-leaning South African AIDS and public health activists, the questioning of the link between the HIV virus and AIDS was what went beyond the pale. It was this strand

of the dissident critique which was perceived to be discontinuous with Western science. The question remains: Why did President Mbeki's deployment of race and nationalist rhetoric in his challenge to mainstream AIDS science fail to win widespread public support?

### **AIDS and the limits of 'race talk'**

Given the history of South Africa, it is perhaps not surprising that race and cultural identity came to assume such a central place in public discourses on AIDS. By the time AIDS began to take such a visible toll on South Africa, the country had barely surfaced from apartheid, a political system characterized by extreme forms of social and economic inequalities and ideological domination that systematically denigrated and dehumanized black people. As a result of this history, as well as colonial legacies of deep distrust of Western science and modernization policies, President Mbeki was able to make the claim that AIDS was being interpreted through a profoundly racialized (and racist) lens: that African sexualities are 'dysfunctional', and Africans are to blame for their morally irresponsible and destructive sexual behaviour. President Mbeki no doubt felt compelled to challenge these racist readings of black bodies and sexualities, as did many other African nationalists. It would seem that AIDS has become a Rorschach, an ideological screen upon which a range of fears and fantasies have been projected. Mbeki's response suggests that he believes that there is a widespread view that it is the socially irresponsible, excessive and immoral sexual practices of Africans which are the root cause of the spread of the AIDS pandemic: the victim is to blame.

Although HIV/AIDS exists among white, middle-class heterosexual communities throughout the world, the stigma of its early associations with homosexuals, bisexuals, blacks, sex workers and drug users has continued to stick. This troubling genealogy of the disease continues to shape the AIDS debate in South Africa. It explains the intense sense of shame associated with AIDS among many South Africans. It also explains the attraction of dissident AIDS science and nationalist views, especially among young, educated black South Africans. A TAC activist spoke of significant support for Mbeki's dissident views among intellectuals and educated township youth, while in the rural areas she encountered widespread denial and myths. By December 2002, it appeared that while TAC may have won the 'Nevirapine battle', and in the process mobilized thousands of black mothers seeking to ensure the survival of their babies, it had not yet won the war against misinformation, fear, denial, silence and shame.

For those HIV-positive, unemployed and working-class black mothers who joined TAC, cultural nationalist arguments did not resonate with their all-too-real experiences of contracting the virus from HIV-positive men and losing children to AIDS, a tragedy that they believed could be averted through prevention of mother-to-child transmission (PMTCT) programmes. For example, V, a young, black female TAC volunteer, tells the story of how, following the trauma of rape by an uncle who later committed suicide, she was diagnosed with AIDS, hospitalized and told that she 'must wait for my day of death'. V eventually joined TAC and received anti-retroviral therapy treatment (ART). For V, TAC literally saved her life – 'now I can stay alive for a long time. I have my whole life' – and the organization became the family that she lost when she was diagnosed HIV positive – 'Mandla and Zackie are like my brother and father'. V's account of her confrontation with AIDS and the spectre of death suggests why the abstract and ideological language of the cultural nationalist response to AIDS and AIDS science did not resonate for her. It also draws attention to the experiential dimensions of belonging that TAC is able to provide for HIV-positive people who, once they reveal their HIV status, are often exposed to stigma and rejection from their families and communities.

This traumatic experiential dimension of AIDS draws attention to the limits of ideological mobilization in terms of shaping peoples' understanding of their identities and their place in the world; their citizenship. Nationalism or 'imagined communities' cannot easily be conjured up in the absence of experientially based understandings and social realities. How, then, was TAC able to catalyse and mobilize community belonging and civic action in a time of AIDS?

### **The Treatment Action Campaign**

TAC was established on 10 December 1998, International Human Rights Day, when a group of about fifteen people protested on the steps of St George's Cathedral in Cape Town to demand medical treatment for people living with the virus that causes AIDS. By the end of the day, the protesters had collected over a thousand signatures calling on the government to develop a treatment plan for all people living with HIV. [...] The international face of the organization is Zackie Achmat, a fortysomething Muslim former anti-apartheid and gay activist. He is also a law graduate and an openly HIV- positive person. Until very recently, Achmat had made it known publicly that he refused to take ART until it was available in the public health sector. [...]

When TAC was founded, it was generally assumed that anti-AIDS drugs were beyond the reach of developing countries, condemning 90 per cent of the world's HIV-positive population to a painful and inevitable death. While TAC's main objective has been to lobby and pressurize the South African government to provide AIDS treatment, it has been forced to address a much wider range of issues. These issues included tackling the global pharmaceutical industry in the media, the courts and the streets; fighting discrimination against HIV-positive people in schools, hospitals and at the workplace; challenging AIDS-dissident science; and taking the government to court for refusing to provide PMTCT treatment programmes in public health facilities. Rather than responding to AIDS from a cultural nationalist perspective, TAC mobilized within working-class black communities and the trade union movement, and used a variety of methods to pressurize the global pharmaceutical industry and the South African government to provide cheap ARV drugs. [...]

Soon after its establishment, TAC, together with the South African government, became embroiled in a lengthy legal battle with international pharmaceutical companies over AIDS drug patents and the importation of cheap generics to treat millions of HIV-positive poor people in developing countries. As a result of highly successful global and national media campaigns, TAC managed to convince international public opinion, and the Pharmaceutical Manufacturers Association (PMA), that it was moral and just for drug companies to bring down their prices and allow developing countries to manufacture generics. [...]

Much of TAC's energy, however, was devoted to more local matters: mobilizing poor and working-class communities, using the courts to compel the Ministry of Health to provide ARVs at public facilities, and campaigning to protect the autonomy of scientific institutions from government interference. Although grass-roots mobilization was primarily in working-class areas, TAC's organizational structure and support networks crossed race, class, ethnic, occupational and educational lines.

TAC volunteers were involved in AIDS awareness and treatment literacy campaigns. In addition, TAC disseminated reports, scientific studies, web- site documents and media briefs refuting government claims that ARV treatment was dangerously toxic, ineffective, too costly and could not be implemented owing to infrastructure and logistical problems such as inadequate management structures, lack of trained staff and so on. The organization also came out in strong support of doctors, hospital superintendents, medical researchers and the MRC, who, by virtue of their report findings or provision of ARV treatment, found themselves on the wrong side of government, and subject to high-level political interference and intimidation.

### **AIDS activism and ‘globalization from below’**

TAC’s mode of activism could be described as ‘grassroots globalization’ or ‘globalization from below’. Following the precedent of the divestment campaigns of the anti-apartheid struggle, TAC activism straddled local, national and global spaces in the course of struggles for access to cheaper AIDS drugs. This was done through the courts, the Internet, the media and by networking with South African and international civil society organizations. Widely publicized acts of ‘civil disobedience’ also provided TAC with visibility within a globally connected post-apartheid public sphere. By concentrating on access to ARVs for working-class and poor people, TAC was participating in a class-based politics that departed significantly from the cultural nationalist/identity politics promoted by the new ruling elite of Mbeki and Mokaba. It was not coincidental that the Congress of South African Trade Unions (COSATU), having lost thousands of workers to the pandemic, readily joined the TAC campaign.

[...] TAC was also able to rely on support from middle-class business professionals, health professionals, scientists, the media and ordinary South African citizens, and used rights-based provisions in the South African constitution to secure poor people access to AIDS treatment. These legal challenges created the space for the articulation of a radical democratic discourse on health citizenship. TAC’s grass-roots mobilization and its legal challenges blurred the boundaries between the street and the courtroom. The Constitutional Court judges could not but be influenced by growing public support for TAC, which achieved extraordinary media visibility and shaped public opinion through sophisticated networking and media imaging. They were able to give passion and political and ethical content to the ‘cold letter’ of the constitution and the ‘cold facts’ of AIDS statistics.

## Pills are my life

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In : Steven Robins (2008). *From Revolution to Rights in South Africa. Social Movements NGOs & Popular Politics*, Scottsville, University of KwaZulu-Natal Press, 134-139

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‘Thembeke’ (not her actual name) is a thirty-something HIV-positive TAC activist in Lusikisiki, a small rural town in the former Transkei homeland in the Eastern Cape. She told me that discovering her HIV status and joining TAC and the MSF ARV treatment programme had dramatically improved her life: ‘Thanks to TAC and MSF I’m flying. I’ve got wings to fly.’ I recall being shocked when Thembeke first described her experience of HIV as a ‘blessing in disguise’. Yet, as I got to know her, it became clear that being tested for HIV, joining TAC and the MSF ARV programme in Lusikisiki had indeed ushered in for her a new and better life. She recalled the trauma of sexual abuse by an uncle as a young girl, being sent away to stay with her mother’s friends as a teenager while her younger sister stayed at home and attended a good ‘model C’ school. She also tearfully recollected a violent gang rape by four youths and being unable to tell her parents about it because she feared that they would not believe her. Her rape led to pregnancy and her decision to have an abortion, while her later discovery of her HIV status led to her decision to have a sterilisation operation.

After I had my VCT [Voluntary Counselling & Testing] the counsellor told me that I’m HIV positive and that all my dreams are finished and I’m going to just die. And then they told me that all my kids would be HIV-positive. It’s either I’ll condomise, or if my husband sometimes doesn’t want to use condoms then I should just use sterilisation. That’s the way that they can help me. Because the more babies I have the more quickly I will die.

Thembeke’s life story included accounts of child sexual abuse, rape, abortion, sterilisation and the onset of serious debilitating illness, culminating in her discovery in 2001 that both she and her baby were HIV-positive: ‘I was very sick but then I found TAC and MSF and my life changed ... *TAC is my mother, MSF is my father*’. While her mother, who was a nurse, subscribed to the minister of Health’s controversial nutritional diet of garlic, lemons, olive oil and the ‘African potato’ for HIV-positive people, Thembeke’s involvement with MSF and TAC led to her rejection of these alternative and traditional remedies and her participation in antiretroviral therapy at the MSF programme in Lusikisiki. The health minister’s promotion of this nutritional advice was interpreted by AIDS activists such as Thembeke as tacit support for the dissidents’ claims that ARVs were dangerously toxic. As her health improved under ARV treatment, Thembeke became integrated into the closely-knit and supportive network of TAC activists and mSF doctors and nurses. She learnt AIDS awareness training skills and acquired basic scientific knowledge about HIV/AIDS, prevention and treatment. She was also personally handed her ARVs by former president Nelson Mandela when he officially launched the ARV programme in Lusikisiki in 2003. When I met her in 2004 she was being headhunted by NGOs in the Eastern Cape but had decided to stay on as an mSF treatment literacy practitioner (TLP) and youth organiser in Lusikisiki. She spoke about her work as ‘preaching the gospel’.

4. Is knowing enough? The sluggish start of pre-exposure prophylaxis (PrEP)

# Why is no one on the first treatment to prevent HIV?

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In : Glazek Christopher (2013), “Why is no one on the first treatment to prevent HIV?”, *The New Yorker*, <https://www.newyorker.com/tech/annals-of-technology/why-is-no-one-on-the-first-treatment-to-prevent-h-i-v>

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In November, 2010, the *New England Journal of Medicine* [published the results](#) of a three-year clinical trial, funded by the National Institutes of Health, announcing the arrival of a treatment that could reduce the risk of contracting H.I.V. by more than ninety per cent. The treatment involved a blue, oval pill containing emtricitabine and tenofovir. Marketed under the brand name [Truvada](#), the pill was synthesized in 2004 by Gilead Sciences, the world’s largest producer of branded H.I.V. drugs, and has been used in combination with other antiretrovirals as a primary treatment for people living with *AIDS*. The N.I.H. team discovered that a daily dose of Truvada not only suppressed the virus in people who were already infected but also prevented healthy people from contracting H.I.V. in the first place. Following the N.I.H. study, which tracked gay men in Peru, Ecuador, Brazil, South Africa, Thailand, and the United States, additional trials showed the drug to be effective for heterosexual [men](#) and [women](#), as well as for [injection-drug users](#). Researchers called the treatment “pre-exposure prophylaxis,” or PrEP for short. Others have called it “the new condom.”

On the day the N.I.H. announced the results of the PrEP study, the research team received a congratulatory phone call from President Obama. Shortly thereafter, *Time* put PrEP in the first slot on its list of the year’s [top medical innovations](#). Dr. Robert Grant, a professor at the University of California San Francisco and the N.I.H. study’s lead scientist, braced for a stampede. He told me, “The evening before we announced, we had meetings with the leadership of public health in California, and they were thinking, as we were, that there was going to be a rush, that everyone was going to descend on the clinics.” The Centers for Disease Control issued interim usage guidelines, despite the fact that the treatment was more than a year away from formal F.D.A. approval. The C.D.C. knew that some doctors were already prescribing Truvada for prevention off-label, and it expected more to follow suit.

But, in fact, adoption of the drug has been slow. According to Dawn Smith, a biomedical interventions implementation officer in the C.D.C.’s epidemiology branch, at least half a million Americans are good candidates for PrEP—meaning that they are at high risk for contracting H.I.V. through sexual activity—yet only a few thousand Americans are receiving the treatment. “As in most fields, many clinicians don’t want to be the first one out of the gate,” Smith said. Salim Karim, the chair of United Nations’ *AIDS* Scientific Expert Panel and the director of the Centre for the *AIDS* Programme of Research in South Africa, thinks that doctors’ hesitation may not have anything to do with sexual health. “Clinicians fundamentally have difficulty giving healthy people drugs,” he said. “This is not unique to H.I.V.” Meanwhile, despite repeated demonstrations that Truvada provides protection from H.I.V., an estimated hundred and fifty thousand Americans, more than a third of whom are in their teens and twenties, have become infected with the virus since the results of the study were released.

The medical community’s reluctance to prescribe Truvada—and patients’ reluctance to request it—also stems from a bitter fight over the treatment. Critics have questioned PrEP’s safety, efficacy, and cost, and

have accused the government of colluding with the drug manufacturer at the expense of public health. Regan Hofmann, the former editor-in-chief of *Poz*, a magazine for people living with *AIDS*, called PrEP a “profit-driven sex toy for rich Westerners.” Michael Weinstein, the head of the *AIDS* Healthcare Foundation (A.H.F.), the world’s largest *AIDS* organization and the primary-care provider for more than two hundred thousand patients around the world, predicted a public-health catastrophe. “The applause for this approach shows just how disposable we consider the lives of gay men,” he [wrote](#). When I interviewed Weinstein, he claimed the studies were “rigged” and that PrEP was essentially a plot by Gilead to force young people into buying unnecessary medication, and that it was going badly because A.H.F. wasn’t letting the company get away with it.

These kinds of claims helped to shape perceptions of the drug among patients, doctors, and journalists. At an open F.D.A. hearing in May, 2012, busloads of A.H.F. employees showed up to make statements against PrEP, raising questions about the drug’s side effects, its price tag, its potential to incite risky behavior, its failure to prevent other S.T.D.s, and the possibility that imperfect adherence to the pill’s daily regimen would lead to the spread of a Truvada-resistant strain of H.I.V. Though data from the studies largely contradicts these criticisms, they were widely circulated. “I think the advocacy that A.H.F. did was very effective,” Weinstein told me. “We were quoted in virtually every article that was written.”

Gilead’s efforts to promote Truvada for PrEP treatments have been somewhat meagre. “In any other kind of F.D.A. approval, there would have been beautiful ads, lots of TV, and lots of press touting the fact that this was the new thing to keep people protected from H.I.V.,” said Ernest Hopkins, the director of legislative affairs for the San Francisco *AIDS* Foundation. “Gilead chose not to do that.” According to Jim Rooney, Gilead’s vice-president of medical affairs, the company “spends several million dollars” on educational initiatives related to PrEP, delivered through third-party groups, but it “does not view PrEP as a commercial opportunity.” Truvada is already a blockbuster drug for Gilead; it earned the company [more than three billion dollars in global sales in 2012](#). As Rooney notes, “The role of antiretrovirals in H.I.V. prevention is not yet defined and not yet broadly accepted.” Although Gilead has donated drugs to researchers working on PrEP, it has not undertaken its own study. According to Jim Pickett, the director of prevention advocacy at the *AIDS* Foundation of Chicago, “Pharmaceutical companies had to be dragged into new prevention research. They weren’t excited about it. They didn’t want to do it.”

PrEP’s main problem is that many public-health officials believe people will see it as a substitute for condoms. *Out* magazine provoked a backlash when it [printed a positive report](#) on PrEP in early September, called “Is This the New Condom?” Commenters berated the author, Tim Murphy, and accused the magazine of irresponsibly promoting an unproven medicine at the expense of condoms.

Unfortunately, as Grant points out, when it comes to preventing H.I.V. the perceived efficacy of condoms “exceeds their public-health value.” According to the C.D.C.’s Smith, condoms provide a high degree of protection when they’re used consistently, but data shows that [very few people use them consistently enough to derive a substantial benefit](#), and self-reported condom use falls precipitously when people are asked repeatedly if they’re using condoms over an extended period of time. In the data analyzed by the C.D.C., the difference in protection levels for those who sometimes use condoms and those who never use them was not statistically significant.



The corresponding figures for PrEP are much better: while adherence is a concern, as it is with condoms, Truvada offers H.I.V. protection that is more effective than any other method short of abstinence. In the N.I.H. study, for example, 5.2 per cent of the placebo group “seroconverted,” or became H.I.V. positive, compared with 2.9 per cent of the Truvada group. That’s a forty-four-per-cent added protection over-all—better than inconsistent condom use. More impressively, patients who maintained a detectable amount of the drug in their system were protected at a rate of ninety-five per cent. (A later statistical analysis estimated that the drug would need to be taken four times a week to offer protection in that range.) Grant said that people in the study who took the drug four to seven days a week “were absolutely protected. We didn’t have anyone seroconvert in our cohort in the United States.”

Taking Truvada to prevent H.I.V. comes with very few risks. In the N.I.H. study, one in two hundred people had to temporarily go off the pill owing to kidney issues, but even those people were able to resume treatment after a couple of weeks. While bone-density loss occasionally occurs in Truvada takers who are already infected with the virus, no significant bone issues have emerged in the PrEP studies. And though about one in ten PrEP takers suffer from nausea at the onset of treatment, it usually dissipates after a couple of weeks. According to the U.N. panel’s Karim, Truvada’s side-effects profile is “terrific,” and Grant said that common daily medications like aspirin and birth control, as well as drugs to control blood pressure and cholesterol, are all arguably more toxic than Truvada.

Perhaps more important, drug resistance has not been observed in people who were H.I.V.-negative when they began treatment. “We’re not seeing people getting infected who are actually taking the drug,” said Grant. “There are people who take the drug home with them and choose not to take it; they get infected, but you’re not going to get drug resistance from something that stays in a drawer.” Some patients who entered the trials turned out to already have an H.I.V. infection that was too recent to be caught by a blood test. These subjects showed a small amount of drug resistance, which is why the F.D.A. now requires doctors to conduct an H.I.V. test before putting their patients on PrEP. The larger resistance threat, though, comes from the ten million H.I.V.-positive people around the world who take antiretrovirals for treatment, including, in some cases, Truvada. “The best way to prevent drug resistance is to prevent H.I.V. infection entirely,” said Grant. “We know that when we prevent a case of H.I.V., we’re preventing a lifelong risk of drug resistance.”

Whether using PrEP will cause patients to abandon condoms and increase their number of sexual partners isn’t known. Grant insists that the evidence does not support such a conclusion: “Everyone said that if we offer pre-exposure prophylaxis to people, even in a randomized trial, like we did, it’s just going to cause them to have more sexual partners and stop using condoms. We found the opposite: that people had fewer sexual partners and used condoms more.” Then again, participants in the major PrEP studies received free condoms and regular sexual-health counselling. They also may not have been telling the truth about their sexual practices. Ken Mayer, a professor of medicine at Harvard Medical School and Director of H.I.V. Prevention Research at Beth Israel Deaconess Medical Center, believes that some migration away from condoms and toward Truvada is inevitable, but that it wouldn’t necessarily be a bad trade-off, given PrEP’s efficacy and the fact that many of the people likely to go on the treatment don’t use condoms anyway. This squares with my own conversations with people on PrEP: most of them are seeking PrEP not because they wish to abandon condoms but because they already don’t use them. The C.D.C.’s usage guidelines stress that PrEP is something to be taken in addition to using condoms, since PrEP doesn’t protect against other sexually transmitted diseases.

Cost, at least in the United States, has also turned out to be a smaller concern than initially predicted. Smith said, “We were very surprised to find out the insurance companies said, ‘Yes, we’ll pay for it. It’s much more expensive to treat people who have H.I.V. infections.’ ” While a lot of people at high risk for contracting H.I.V. currently lack health insurance, after January 1st many of them will be able to get coverage through Obamacare. And for those who still don’t have insurance or who have unmanageable co-pays, [Gilead provides assistance](#) to purchase the drug, which has a sticker price of thirteen thousand dollars a year.

In the developing world, however, where even delivering cheap generic versions of Truvada can be a challenge, it remains unclear whether diverting resources to prevention on a wide scale makes sense. Mitchell Warren, the executive director of the *AIDS* Vaccine Advocacy Coalition, points out, however, that the same argument was once made against using antiretrovirals for treatment. “Ten years ago, people said you couldn’t provide treatment in Africa: people wouldn’t adhere, it was too expensive, it would create resistance,” he said. “Many of those issues have been addressed—they haven’t all been overcome—and now we have ten million people on treatment.” Making PrEP available, particularly to protect young women in sub-Saharan Africa, said Karim, “is essential to achieving an *AIDS*-free generation.”

Because H.I.V.-positive people who go on antiretrovirals have a drastically reduced risk of transmission, *AIDS* is spreading more slowly than it used to. Weinstein, of the A.H.F., was among the first to attempt to bring antiretrovirals to Africa. He pointed out that there are ten million people around the world on antiretrovirals today, mostly thanks to George W. Bush’s global *AIDS* initiative. “If we can double that to twenty million,” he said, “I think we will have brought H.I.V. under control.” Truvada for prevention, one might conclude, is an expansion of that concept.

One of the problems is that PrEP lacks a built-in constituency to advocate for it. “*ACT UP* is focussed on people already living with *AIDS*,” said Mayer. And while the opponents of PrEP have been loud and persistent, its supporters tend to be stately and circumspect. Many of the arguments made against Truvada, they note, are the same arguments that proponents of abstinence lodged against birth control in the sixties and against condoms in the eighties. “It takes a long time when it’s a medical intervention that has to do with sexual practices,” said Grant. Gilead predicts that it will take five to ten years for PrEP to become widely used in the U.S., by which time Truvada could be off-patent.

When I corresponded again with Pickett, of the *AIDS* Foundation of Chicago, after the publication of the *Out* article and the ensuing backlash, he appeared to disavow some of his enthusiasm regarding PrEP. What opponents needed to understand, he said, was that “no one was really envisioning widespread use of Truvada as PrEP. It really is a niche intervention—which should be targeted and used very strategically. No one wants to hand this out to everyone in a key population.” When pressed, he clarified that he thought Truvada was for anyone in a high-risk group who struggled with monogamy or consistent use of condoms, a delineation that would seem to include millions of people in the United States alone.

While skepticism about PrEP will undoubtedly recede over time, for the moment it remains strong. I was recently speaking with a twenty-six-year-old urban planner living in Brooklyn, who overheard me talking about PrEP. “Oh yeah,” he said, with a worried look. “I’ve heard of that. I saw that piece in *Out*. It said it doesn’t work, right?”

## Awareness and use

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In : Finlayson Teresa et al (2019) “Changes in HIV preexposure prophylaxis awareness and use among men who have sex with men — 20 urban areas, 2014 and 2017,” *Morbidity and Mortality Weekly Report*, 68(27): 597–60 <https://www.cdc.gov/mmwr/volumes/68/wr/mm6827a1.htm>

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In February 2019, the U.S. Department of Health and Human Services proposed a strategic initiative to end the human immunodeficiency (HIV) epidemic in the United States by reducing new HIV infections by 90% during 2020–2030. Phase 1 of the Ending the HIV Epidemic initiative focuses on Washington, DC; San Juan, Puerto Rico; and 48 counties where the majority of new diagnoses of HIV infection in 2016 and 2017 were concentrated and on seven states with a disproportionate occurrence of HIV in rural areas relative to other states. One of the four pillars in the initiative is protecting persons at risk for HIV infection using proven, comprehensive prevention approaches and treatments, such as HIV preexposure prophylaxis (PrEP), which is the use of antiretroviral medications that have proven effective at preventing infection among persons at risk for acquiring HIV. In 2014, CDC released clinical PrEP guidelines to health care providers and intensified efforts to raise awareness and increase the use of PrEP among persons at risk for infection, including gay, bisexual, and other men who have sex with men (MSM), a group that accounted for an estimated 68% of new HIV infections in 2016. Data from CDC’s National HIV Behavioral Surveillance (NHBS) were collected in 20 U.S. urban areas in 2014 and 2017, covering 26 of the geographic areas included in Phase I of the Ending the HIV Epidemic initiative, and were compared to assess changes in PrEP awareness and use among MSM. From 2014 to 2017, PrEP awareness increased by 50% overall, with >80% of MSM in 17 of the 20 urban areas reporting PrEP awareness in 2017. Among MSM with likely indications for PrEP (e.g., sexual risk behaviors or recent bacterial sexually transmitted infection [STI]), use of PrEP increased by approximately 500% from 6% to 35%, with significant increases observed in all urban areas and in almost all demographic subgroups. Despite this progress, PrEP use among MSM, especially among black and Hispanic MSM, remains low. Continued efforts to improve coverage are needed to reach the goal of 90% reduction in HIV incidence by 2030. In addition to developing new ways of connecting black and Hispanic MSM to health care providers through demonstration projects, CDC has developed resources and tools such as the Prescribe HIV Prevention program to enable health care providers to integrate PrEP into their clinical care. By routinely testing their patients for HIV, assessing HIV-negative patients for risk behaviors, and prescribing PrEP as needed, health care providers can play a critical role in this effort.

NHBS staff members in 20 urban areas collected cross-sectional behavioral survey data and conducted HIV testing among MSM at recruitment events using venue-based sampling. Eligible participants completed a standardized questionnaire administered in person by trained interviewers. All participants were offered anonymous HIV testing and incentives for the interview and HIV test. Analysis was limited to eligible participants at risk for HIV infection who were likely to meet clinical indications for PrEP. Specifically, the analysis was limited to MSM who had a negative NHBS HIV test result, did not report a previous HIV-positive test result, had either one male sex partner who was HIV-positive or two or more male sex partners in the past 12 months, and reported either condomless anal sex or a bacterial STI (i.e., syphilis, gonorrhea, or chlamydia) in the past 12 months. PrEP awareness and use were measured differently in 2014 and in 2017. In

2014, participants were asked whether they had “ever heard of people who do not have HIV taking anti-HIV medicines, to keep from getting HIV” and whether, in the past 12 months, they had “taken anti-HIV medicines before sex because you thought it would keep you from getting HIV.” In 2017, participants were informed that PrEP is an antiretroviral medicine taken for months or years by a person who is HIV-negative to reduce the risk for getting HIV and then asked whether they had ever heard of PrEP and whether, in the past 12 months they had taken PrEP to reduce the risk of getting HIV. Log-linked Poisson regression models with generalized estimating equations clustered on recruitment event were stratified by subgroup to estimate prevalence ratios and 95% confidence intervals (CIs) for PrEP awareness and use by year. Stratified models for each subgroup were adjusted for income, health insurance, and region. Analyses were conducted using SAS software.

In 2014 and 2017, 18,610 sexually active MSM were interviewed (9,640 in 2014; 8,970 in 2017) in the 20 urban areas. Of those, this analysis is limited to 7,873 MSM (42%) who had a negative HIV test result but were at risk for HIV infection and likely met the clinical indications for PrEP (3,821 [40%] in 2014; 4,052 [45%] in 2017). From 2014 to 2017, awareness of PrEP among these MSM increased overall from 60% to 90% (adjusted prevalence ratio [aPR] = 1.45; 95% CI = 1.41–1.50) and increased in all urban areas and subgroups. In 2017, >80% of MSM in 17 of 20 urban areas and in most demographic subgroups were aware of PrEP. From 2014 to 2017, use of PrEP among MSM increased overall from 6% to 35% (aPR = 5.66; 95% CI = 4.85–6.61) and increased in all urban areas and in almost all demographic subgroups. Substantial increases in PrEP use occurred among black, Hispanic, and young (aged 18–29 years) MSM from 2014 to 2017. In 2017, the differences in PrEP use between Hispanic (30%) and white (42%) MSM (aPR = 0.91; 95% CI = 0.78–1.06) and between young (32%) and older (38%) MSM (aPR = 0.97; 95% CI = 0.89–1.05) were no longer significant after controlling for income, health insurance, and region. However, the difference in reported PrEP use between black (26%) and white (42%) MSM remained significant after controlling for these three factors (aPR = 0.78; 95% CI = 0.66–0.92). During 2017, PrEP use increased with education and income, and 39% of the MSM who saw a health care provider in the past 12 months reported PrEP use.

## Discussion

From 2014 to 2017, PrEP awareness among MSM in this analysis increased by 50%. More importantly, in 2017, >80% of MSM in all racial and ethnic groups and in 17 of the 20 urban areas were aware of PrEP. This finding is encouraging and suggests that efforts designed to increase PrEP awareness among populations at risk for HIV infection are having a positive impact. These efforts have included media and social marketing campaigns (e.g., Act Against AIDS). In addition, national HIV prevention goals were updated in 2015 to expand efforts to prevent HIV infection using a combination of effective, evidence-based approaches among populations with the highest prevalences of HIV infection, including among black and Hispanic MSM. Thus, continued increases of awareness among MSM, especially among black and Hispanic MSM, are expected.

Although PrEP use by MSM in this analysis increased approximately 500% from 2014 to 2017, only approximately one in three men at risk for HIV infection reported using PrEP. Models examining the impact of PrEP use on incidence predict that the use of PrEP by 30%–40% of MSM with PrEP indications in a community could result in approximately one third of new HIV infections being averted over a 10-year period, with a greater predicted impact if coverage is increased. The reported increase in PrEP use among MSM is promising, but higher coverage is needed to reduce incidence of new infections by 90% within the 10 years of the Ending the HIV Epidemic initiative.

The overall impact and efficiency of PrEP at averting new infections is greater in communities with a high prevalence of HIV. Therefore, efforts focused on increasing PrEP use among black and Hispanic MSM, who have a higher prevalence of HIV infection, might substantially reduce the incidence of HIV infections. The large percentage increases in PrEP use among black and Hispanic MSM in this analysis are promising, but PrEP use in these groups remains low; continued efforts will be needed to meet the goals of the Ending the HIV Epidemic initiative. Because of the structural barriers associated with race that influence access to quality health care, demonstration projects for the Targeted Highly-Effective Interventions to Reverse the HIV Epidemic (THRIVE) program are underway in seven U.S. cities. These projects establish community collaboratives that provide comprehensive HIV prevention and care services for black and Hispanic MSM. Lessons learned from these efforts might help further inform how best to increase PrEP use among these populations.

Some health care providers might be missing opportunities to provide PrEP to patients who would benefit from its use. MSM included in this analysis reported behaviors that put them at substantial risk for HIV infection, yet only 39% of those who saw a health care provider in the past 12 months reported using PrEP. CDC's HIV PrEP clinical practice guideline offers comprehensive information to providers for prescribing and managing PrEP and recommends that health care providers take routine sexual histories of all their patients. However, some providers only take a sexual history if it is related to the patient's complaint and ask nonspecific questions about sex. To increase PrEP use, health care providers might need training and resources to ensure they know how to assess their patients for indications for PrEP and are confident discussing PrEP medication. As part of CDC's Act Against AIDS communication campaign, the Prescribe HIV Prevention program offers an online toolkit to help health care providers use PrEP to prevent new HIV infections among patients at high risk. This toolkit includes resources such as answers to frequently asked questions about PrEP medication and its related clinical care, campaign posters to help raise PrEP awareness, patient materials, a tool to aid health care providers in discussing sexual histories with their patients, and continuing medical education courses on PrEP. To fulfill their critical role in reducing new HIV infections in the United States, health care providers will need to routinely test patients for HIV, link those with HIV infection to care, and discuss HIV prevention options (e.g., condoms and PrEP) with those who are not infected.

The findings in this report are subject to at least six limitations. First, NHBS data do not correspond directly with the criteria for PrEP indication in the clinical guidelines. NHBS uses a 12-month period for assessing risk behaviors versus a 6-month period specified in the clinical guidelines. Second, this analysis used having two or more sex partners in the past year as a proxy for a non monogamous relationship, but these partnerships might not have overlapped in time. Thus, the analysis might include some men without indications for PrEP use. Their inclusion in the denominator might underestimate the percentage of men in NHBS using PrEP. Third, different questions were used to assess PrEP awareness and use in 2014 and 2017. The measure of PrEP use in 2017 was more specific than that in 2014, so estimates of PrEP use increases are potentially underestimated. Fourth, NHBS is not nationally representative and might not be generalizable to all cities, nonurban areas, or MSM. Fifth, because data were not weighted to account for the complex sampling methods used to recruit MSM, estimates might be biased by over- or underestimating subgroups of the population. Finally, data on self-reported behaviors might be subject to recall and social desirability biases. Although the impact of recall bias on the analysis is unknown, social desirability bias might lead to overreporting PrEP awareness and use.

HIV PrEP awareness and use is increasing in the United States among MSM who are at risk for acquiring HIV, but higher coverage is needed, especially among black and Hispanic MSM, to end the HIV epidemic in the United States by 2030. By routinely testing their patients for HIV, assessing HIV-negative patients for risk behaviors, and prescribing PrEP as needed, health care providers can play a critical role in this effort.

## The color line

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In : Hannah Daryl (2017), “My struggle to take anti HIV medicine”, *The New York Times*,  
<https://www.nytimes.com/2017/09/21/opinion/sunday/-truvada-gay-hiv-aids.html>

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I am a 30-something African-American gay man in New York. H.I.V. is constantly on my mind. Not so much my H.I.V.-negative status. Rather, even though I watched my parents die of AIDS when I was young, I still struggle with whether I should take the drug Truvada, a pre-exposure prophylaxis (PrEP) that can protect almost completely against H.I.V.

My father was convicted of manslaughter and sent to prison in 1989, where he contracted H.I.V. No one in my family is exactly sure how. In 1991, six months after he returned home, he died. Less than two years later, my mother also died. I was only 7.

I don't remember my parents in any great detail, but I do remember that people in our rural South Carolina community ostracized my sister and me once they learned our parents were H.I.V. positive. One parent even transferred her daughter out of my second-grade class.

As was true in the early 1990s when my parents died from AIDS, gay black men still account for the highest percentage of new H.I.V. cases in the country. According to the Centers for Disease Control and Prevention, black people made up [45 percent of all H.I.V. diagnoses in 2015](#), though they were only 12 percent of the population. If current transmission rates persist, [half of](#) gay and bisexual African-American men will become infected with the virus during their lifetime.

It's unfortunate, but not surprising, that this problem is particularly acute in the South. Racism at doctors' offices, poverty [and a lack of access to health care](#) play a role in these high infection rates.

These factors have also stymied efforts to market PrEP more successfully to the African-American community. Only 10 percent of all the prescriptions for PrEP have been filled by black people, while white people account for 74 percent.

I was 27 when I first worked up the nerve to ask my doctor for a PrEP prescription. I was there for my fifth annual H.I.V. test, and I'll never forget the look of disgust on her face as she told me why I wasn't a candidate for the drug: I didn't engage in “reckless sex” and I wasn't a “druggie.” She was white and her tone was so thick with judgment that it made my skin crawl. I quickly dropped the subject.

It would be five years before I would broach the subject with a doctor again, even after I had gotten a new one. He was a gay man of color and he initiated the conversation. Instead of telling me why I wasn't right for the drug, we spent the time talking about why I felt that I needed it. I had promised my parents that I would take every precaution against H.I.V., so I put enormous pressure on myself to take it. Plus, it let me be extra cautious about my health and my partner's health. After our conversation, he tested me for H.I.V. and wrote me a prescription.

I carried the prescription in my pocket every day for three weeks before I worked up the courage to have it filled, and even then I didn't go to the drugstore right across from my office. I chose one four blocks away because I didn't want anyone to see me. The very nice pharmacy technician informed me that even with my employer-backed health insurance, my PrEP prescription would cost \$175 a month. Too embarrassed to admit that I couldn't really afford that, I smiled and signed the receipt.

It wasn't until I got back to my apartment and opened the bottle of pills that reality began to set in. Not only was I committing to a new monthly expense, but I was also signing up to take a pill every day, a lifestyle change that I wasn't entirely comfortable with.

My first few weeks on PrEP, I felt fine. Every morning at 8 a.m. my cellphone chimed with a reminder for me to take my pill. I even began to develop a subtle sense of pride in knowing that although I was having sex only with my partner, I was upholding my word to my parents. But as the one-month mark approached, I began to have serious doubts about why I was taking PrEP. After all, I wasn't having sex with men other than my partner; same for him. We still used condoms, despite having been together for several years.

I recognize that PrEP is effective and agree that it should be available to people who want to take it. But after about a month of taking it off and on, I just stopped. I couldn't get over the psychological barrier that somehow I was weakening my body by training myself to rely on pills. Instead, my partner and I decided to take the precautions we're comfortable with.

There are also cultural reasons for why I abandoned the drug. Like many other people from low-income families in the rural South, I didn't grow up understanding that drugs could prevent sicknesses. The only people who took medicine around me were those who were already ill. Instead, bleach was our anti-pathogenic weapon. And because my parents contracted H.I.V. before our understanding of the virus evolved to what it is today, a hospice nurse bleached everything in our house at least once a day.

As sad and ignorant as that may seem, losing my parents to AIDS has instilled in me a deep skepticism of doctors, medicine and even hospitals. And while this is rooted in my own experience, [studies show](#) that blacks still hold deep suspicions about the healthcare industry and we report higher instances of racial bias at doctors' offices than other groups. The Tuskegee trials, where federal researchers followed African-American men infected with [syphilis](#) and withheld treatment so that they could see the disease take its course, and other racist medical experiments, have left a long shadow.

Retention rates for PrEP are deplorable — one study showed usage in Mississippi dropped by [15 percent over a three-month period](#) — and it's clear to me why. I had guilt and carried emotional baggage. I also felt alone in my journey. There was no PrEP community that I could find with which I could share my anxieties, no PrEP “sponsor” to call and discuss my night terrors or fatigue.

To get more people to take the drugs and stay on them, the medical community needs to acknowledge the variety of experiences that contribute to dropout rates. It ought to create better support systems for people who are just starting to take the drug, like regular check-ins with nurses and easily accessible communication platforms so that people can connect with one another and discuss their experiences. It's not that we're all just irresponsible, as I recently heard a table of white L.G.B.T. activists bemoan. Some of us are also dealing with deep trauma. We can't lose sight of that.