8-29-2024

From G.R.I.D. to AIDS & COVID-19 to Long-COVID: Naming and Defining Biological Threats

J. Ricky Price
St. John Fisher University, jprice@sjf.edu

Publication Information

Price, J. Ricky (2024). "From G.R.I.D. to AIDS & COVID-19 to Long-COVID: Naming and Defining Biological Threats." *Emancipations: A Journal of Critical Social Analysis* 3.2.

From G.R.I.D. to AIDS & COVID-19 to Long-COVID: Naming and Defining Biological Threats

Abstract

This article uses the history of the early U.S. case definition of AIDS to question the imperatives in the newly developed Long-COVID (LC) definition. Doing so allows us to think through the role of case definitions in producing meaning in our world and to consider what we can learn about the politics of knowledge creation. By examining the porous boundaries of identity, institutions, and AIDS and placing this history in relation to LC, I argue that the state is doing more than describing and diagnosing these institutional practices, but that hybrid identities are *produced* by the state through these practices like naming and defining. Comparing these two events in public health reveals the state to be a primary—perhaps the primary—agent in elaborating the contours of identity through disease. I employ an analytic framework based on the institutionalization of "identity stories" established by political scientist Clarissa Rile Hayward to argue that the case definition is a central site where knowledge about disease and identity is built into the structure of political institutions. Identifying how this process happens within institutions provides important political lessons for our current moment and offers opportunities for resistance to health inequities.

Disciplines

Political Science

Comments

Price, J. Ricky (2024) "From G.R.I.D. to AIDS & COVID-19 to Long-COVID: Naming and Defining Biological Threats," *Emancipations: A Journal of Critical Social Analysis*: Vol. 3: Iss. 2, Article 6.
Available at: https://scholarsjunction.msstate.edu/emancipations/vol3/iss2/6

Creative Commons License

Emancipations: A Journal of Critical Social Analysis

Volume 3 | Issue 2 Article 6

July 2024

From G.R.I.D. to AIDS & COVID-19 to Long-COVID: Naming and Defining Biological Threats

J. Ricky Price
St. John Fisher University, jprice@sjf.edu

Recommended Citation
Price, J. Ricky (2024) "From G.R.I.D. to AIDS & COVID-19 to Long-COVID: Naming and Defining Biological Threats," *Emancipations: A Journal of Critical Social Analysis*: Vol. 3: Iss. 2, Article 6.
Available at: https://scholarsjunction.msstate.edu/emancipations/vol3/iss2/6

From G.R.I.D. to AIDS & COVID-19 to Long-COVID: Naming and Defining Biological Threats

Cover Page Footnote

I am deeply grateful to Chelsea Ebin, H. Howell Williams, Matthew Kirsch, Hannah Dickinson, Jack Vimo, Miriam Ticktin, Vicki Hattam, Jasmine Rault, and Ann Snitow for their support and feedback on this article.

As COVID-19 evolves from a pandemic to an endemic condition, it becomes a problem to be managed, minimized, and prevented rather than a problem to be solved or eradicated. One of the first steps in the process of containment is naming and defining viral and biological threats. The state plays a central role in determining who is at risk and how that risk is mitigated. How the state defines and organizes resources around emerging health threats determines the boundaries of our actions, choices, and opportunities for organizing our lives. One key element in this process is how the state and its scientific institutions define the boundaries of a threat, who is determined to be at risk, and the development of an appropriate state and individual response, all of which begins with a case definition. Therefore, the case definition of a disease offers a vital site to analyze how knowledge is produced between our bodies and the state.

The case definition operates as a form of institutional storytelling. In this paper, I use the history of the early case definition of AIDS to question what is at stake in the newly developed definition of Long-COVID (LC). This comparison is productive for two central reasons. First, contestations over defining the boundaries of HIV help us understand the parameters of current contestations on the boundaries of COVID and LC. The management of HIV is an important historical institutional development in U.S. healthcare policy. It explains how the state understands our bodies and organizes resources based on risk and identity. These policy imperatives are challenged in unforeseen ways amidst the novel COVID-19 virus. The case definition has long-lasting effects on identity production and access to treatment, which leads to the second reason for making this comparison: the authors of the LC definition reference the inequities created by the AIDS case definition as a guiding principle in the development of the LC definition. The comparison helps show how institutional change occurs by demonstrating how institutions have learned to use and conceptualize risk as an epidemiological tool over the last forty years and the deployment of those concepts through seeming inconsequential decisions like naming and defining. AIDS and LC are both long-term communicable illnesses that require regular healthcare intervention. They are both syndromes that use our bodies against ourselves, making each uniquely difficult for the state to define, manage, and contain. By studying the development of the case definition of both illnesses, we can better understand how the state conceptualizes equity in relation to healthcare more broadly.

Furthermore, the distinction between syndromes and diseases is important to understand the comparison of case definitions between AIDS and LC I outline in this paper. The case definition of AIDS, established in 1982, came four years before the viral agent HIV was discovered (Grmek 1990). Once a blood test was developed that could accurately detect the virus, new therapeutic and preventative fronts opened in the fight against HIV. Scientists were able to quickly identify the viral agent COVID-19, develop accurate, rapid testing for the virus, and sequence the virus's genome, leading to reliable vaccines (NIAID 2024).

Four years into the COVID-19 pandemic, LC is in the initial stages of its case definition development.[1] Unlike HIV and COVID-19, which are viruses and relatively easy to detect with current technology, AIDS and LC are syndromes. The LC definition is an amalgamation of symptoms and effects from multiple COVID diagnoses still coming into focus. In contrast, the AIDS definition is related to the depletion of your immune system by measurement of white blood cells (MMWR 2014). While these two

---

[1] The CDC's (2024) short defines LC as a "chronic condition that occurs after SARS-CoV-2 infection and is present for at least 3 months". LC includes a wide range of symptoms or conditions that may improve, worsen, or be ongoing.

pandemics operate drastically differently on a biological level—the case definitions of these syndromes can help us make sense of the way institutions understand our identities and how they develop responses to biological threats.

To examine this history, I draw upon archival work and interdisciplinary scholarship around HIV/AIDS. Doing so allows us to think through the role of case definitions in producing meaning in our world and to consider what we can learn about the politics of knowledge creation. By examining the porous boundaries of identity, institutions, and AIDS and placing this history in relation to LC, I argue that the state is doing more than describing and diagnosing these institutional practices; the state produces hybrid identities through these practices. Comparing these two events in public health reveals the state to be a primary—perhaps the primary—agent in elaborating the contours of identity through disease. The institutional story that undergirds these hybrid identities starts with the definition. Once that definition is established and embedded into our institutions, laws, and everyday practices, it becomes increasingly intractable to dislodge the story from politics and policy.

The case definition is not a neutral, objective, scientific descriptor whose utility is based solely on diagnosis. Rather, it operates as a political tool of institutions. It is a tool that not only determines who is at risk and what resources they deserve but further defines the boundaries of our agency with our bodies in the world. It outlines our choices and how we understand ourselves as (dis)abled, (un)healthy, at-risk/safe from illness and disease. This comparison helps make clear how those lines are drawn through everyday institutional practices.

We are all now living with COVID-19. How we define this relationship in the coming years will not only determine the lifespans of millions of people; the outcome of these institutional decisions will also guide and structure how we understand ourselves in the world. The case definition operates as a link in the interpellation of our identities while simultaneously constructing the regime of knowledge that structures the way we come to know our identity in the first place.

Focusing on case definitions as storytelling invites us to think about identity production through discourse, and I employ the analytic framework established by political scientist Clarissa Rile Hayward. In her 2013 book, *How Americans Make Race: Stories, Institutions, Spaces*, in which she argues, "People reproduce identities, not just by telling and retelling the stories from which they were constructed, but also by *institutionalizing* those stories: by building them into norms, laws, and other institutions" (13-14). These stories become the basis for policies that have material effects on people where they live and breathe. Hayward explains, "People reproduce identities, in addition, by *objectifying* identity stories: by quite literally building them into material forms…that social actors experience with their bodies as they engage in political activity" (14). Thinking with Hayward's work, I argue that the case definition is a central site where knowledge about disease and identity is built into the structure of institutions. Scientific institutions employ the case definition to develop norms about how to treat an emerging threat by determining which identities are at risk, which identities are safe, which identities need preventative measures, which identities need to be surveilled, which populations deserve resources, and so on. These norms are then encoded in the law, thereby institutionalizing identity stories. Understanding this process underscores how case definitions can produce new ways of being in the world as they map existing social identities onto risk categories and create new hybrid identities that determine one's life chances.

The case definition does not merely describe a problem and prescribe a treatment; it *produces* hybrid identities by demarcating the boundaries of healthy/unhealthy, legal/illegal acts, and risky /safe behaviors. These case definitions and other storytelling practices of institutions situate risk as natural—that some communities have riskier environments to navigate for reasons beyond the political—understanding the minutia of naming and defining works to unyoke the idea that scientific practices are merely descriptive rather than productive. It also highlights potential sites of resistance to institutional inequities beyond these two pandemics.

This paper starts by examining the development of the AIDS case definition and the contestations that led the CDC to change the case definition to include women's symptoms. From there, I analyze the establishment of the LC definition in relation to this history to understand better how this process will transpire in the coming years. The first decade of the AIDS epidemic offers political lessons on how to think about emerging and unknown threats amidst our ongoing crises. If we understand the case definition as an institutional identity story in addition to a political tool for surveillance and diagnosis, it becomes clearer why HIV/AIDS seemingly began as a "gay disease" in the 1980s and transformed into one of the leading causes of death, globally for women of reproductive age (WHO 2015, UNAIDS 2022). In the case of AIDS, the virus did not merely decide to change host populations from gay men to Black women; instead, public health institutions have changed the populations they focused upon through revisions and reforms to their practices.

In the case of LC, the definition focuses on notions of equity that stem from the institutional lessons learned from HIV. I show, however, that despite efforts to avoid past mistakes that led to inequities in the U.S. healthcare system, the CDC is reproducing inequities in different ways by deploying identity stories about COVID. These stories create the discursive and material reality of who has LC and who does not, who is monitored and who is not, and who receives resources and who does not. To be diagnosed with LC—or any long-term illness—alters your choices and intersects with your race, gender, class, sexuality, and citizenship status to determine the outlines of what is possible for your life. This paper contends that institutional decisions, like case definitions, organize our lives in ways that make these structured inequalities seem to be natural conditions of our environment.

HIV/AIDS culture and politics have been deeply researched by a range of interdisciplinary scholars, HIV community groups, and activists. This article contributes to this complex body of literature by showing how seemingly benign institutional practices produce the conditions of politics that shape the horizon of what is possible. I demonstrate how these small institutional moves—i.e., naming, defining, and categorizing, not only set the terrain of HIV/AIDS politics but also represent the first cycle of objectification and institutionalization of the HIV/AIDS epidemic. I contend that we are in the first cycle of objectification and institutionalization of LC, and these institutional practices will affect policy and politics for years to come. This analysis deepens our understanding of this history and speaks to our present moment as we navigate the next stages of this pandemic.

Science, Identity, and the State

The development and maturation of the sciences of virology and genetics occurred concurrently with the HIV/AIDS crisis. Due to breakthroughs and new technologies, like the electron microscope and DNA testing, scientists could observe our bodies' microscopic universe in novel ways. New emerging viral threats, like HIV/AIDS, became targets of research and scientific development. The research that came out of virology and genetics fundamentally changed the way that science understands our bodies, how they work, and how to intervene upon them. These developments were also coming off the heels of the liberatory identity-based movements of the 1960s and 1970s. Black power movements, Gay and Lesbian rights movements, Women’s rights, workers' movements, and Indigenous movements all led to a re-articulation of the relationship between identity and the state. It was also in the 1980s and 90s when Queer studies, Black studies, Ethnic studies, and other identity-based studies were established in universities across the U.S. The scholarship that developed out of this milieu deeply interrogates the relationship between our identities, science, and the state. Attending to this literature demonstrates the ways that historically marginalized groups navigated the institutional politics of medical discourse.

Sociologist Troy Duster published Backdoor to Eugenics in 1990, a clarion call about the dangers of associating genetic science with racial and gender identity. He warned that the production of genetic knowledge mirrored the production of eugenics theories in the early 20th century and argued that we should understand identity through the “social concerns of an age” rather than “the scientific status of new knowledge-structure of genetics” (Duster 1990, vii). Genetic breakthroughs forced a rethinking of the history and development of eugenics and the post-civil-war development of new sciences centered on race, gender, and sexuality. Genetic essentialism replaced bio essentialism to challenge notions of social construction theory. Duster reminds us that this dance between science, identity, and the state in constructing reality is an ongoing process that takes new and novel forms with each scientific breakthrough and every wave of contestation.

Beyond genetics, scholars have long noted that medical discourse and scientific practices have tremendous impacts on the construction of the material world. Scholarship on identity and the state began focusing on the AIDS crisis throughout the 1980s and 1990s. Paula Treichler (1987, 1999) and Steven Epstein (1996) grappled directly with the politics of identity formation and the production of scientific knowledge about our bodies and disease. Treichler describes AIDS as an "epidemic of signification," rooted in language, warning scholars that "We cannot therefore look 'through' language to determine what AIDS 'really' is. Rather, we must explore the site where such determinations *really* occur and intervene at the point where meaning is created: in language" (Treichler 1987, 263). Her later work questioned how and why women were excluded from these medical definitional practices. Her work shows how the focus on gay sex by the CDC led to omissions of how HIV was transmitted to women through heterosexual sex and calls into question the actual function of public health statistics, "…public health surveillance of illness and disease typically wants to know two things—who gets sick and how they get sick—this yielding the classification of each case into a "risk group" and a "mode of exposure" (Treichler 1999, 242). Epstein highlighted how medical discourse sutured gay male identity together with the new viral threat, "Partly through the power of the medical definitional process, partly through the ideological work of the opponents of gay liberation, gay men increasingly came to be equated with the emergent epidemic—it came to constitute part of their social identity" (Ibid, 53). Epstein and Treichler unmask the politics of science at play and point out the institutional practices from doctors, researchers, journals, and policymakers that create the building blocks for identity stories to proliferate and reproduce knowledge about our bodies.

Working from poststructuralist, queer, and women-of-color feminist orientations, scholars like Siobhan Somerville produced scholarship that showed in intricate detail how modern notions of race, gender, and sexuality were co-constituted by scientific discourse from the nineteenth century. She writes in 1994 that medical discourse "…not only became one of the few sites of explicit engagement with questions of sexuality during this period [19th Century U.S.] but also held substantial definitional power within a culture that sanctioned science to discover and tell the truth about bodies" (Somerville 1994, 244). Sommerville argued that the boundaries of whiteness were defined in part through this medical discourse that differentiated whiteness and maleness from black-ness, woman-ness, and queer-ness (Somerville 2000). In Hayward's framing, this medical knowledge creates a norm about what defines certain bodies and objectifies these "scientific" differences through medical and legal codes. This is a central way that identity stories about race, sexuality, and gender are established, contested, and reproduced.

Work in the 2000s moved beyond the initial onset and the populations the CDC focused on and followed the epidemic's effects into populations outside the U.S. healthcare system, in poor communities in the U.S., and across the Global South. Access to affordable drugs became central to AIDS politics, as scholars such as Cathy Cohen demonstrated at the time. Cohen's 1999 book *The Boundaries of Blackness* demonstrated how AIDS became a "cross-cutting" issue within Black communities and that the stigma of gay male sexuality within this racial context "…put into full view the question of who is "worthy" of support by the larger black community, specifically by its indigenous political organizations" (Cohen 1999, 14). Following Cohen, we should address the tension between how communities define and identify themselves in relation to institutional definitions and resources. Jennifer Brier's *Infectious Ideas* recounts the early U.S. governmental response to the crisis and demonstrates how, despite Regan's silence on HIV/AIDS, the U.S. state began formulating policy immediately on the epidemic out of public view (2011). Brier examines how AIDS was transforming the state and marginalized populations. Identity stories, once institutionalized, define community-based identity politics and state-based policy.

Adam Geary's work continues this thread in *Anti-Black Racism and the AIDS Epidemic,* where he develops the idea of "state intimacies," which he defines as the "violent intimacy of the racist state," arguing that the state structures Black life in a way that makes Black communities more vulnerable to risks. In opposition to the messaging of the CDC, which defines Black and Latino gay men as "high-risk populations" for HIV (Geary 2014, 2). Further stating that "The AIDS epidemic is structured not by the *deviant* behaviors or relations that people engage in, but by the *unequal and violent conditions* which they are forced to live and that are embodied as ill-health and vulnerability to disease" (Ibid). The definition of the disease carries much more weight than mere diagnosis. As these scholars explain, to have your body fall within the case definition of AIDS has tremendous material effects on your position in your community, your access to healthcare, and the choices for your life. These scholars all promote the idea that the boundaries of our identities and our rights are deeply imbricated within scientific and medical practices. Decisions about diagnosis, definition, and care by the state produce new ways of being in the world, new inequalities, and new movements. Defining disease is a central practice in producing our identities in relation to the structures within which our bodies are situated.

Contemporary scholarship continues these imperatives through the robust historicization of the early years of the epidemic (Schulman 2021, Juhasz and Kerr 2022), to new examinations of the establishment of the "first case of AIDS" infamously described as Patent Zero (McKay 2017), to the first Federal response, the passage of the Ryan White ACT (Resnik 1999 and Renfro 2024). The tension between state identification and the "at-risk communities" is central to these works. From the activism that contested the CDC definition and built a global movement to the epidemiology practices that framed one man as the original vector of HIV to the "innocent boy" with hemophilia, Ryan White, whose death from AIDS-related illness helped to pass the first Federal response to the crisis—all of these, can be seen from Hayward's framework as stories that make up part of this complex process of the politics of identification.

Furthermore, the consequences of framing communicable diseases through the lens of individual risk and behavior have led to the criminalization of HIV and sickness more broadly (Stanley and Smith 2011, Hoppe 2018, Day 2023, McClelland 2024). This scholarship speaks to how these hybrid identities are criminalized and that prisons themselves become central vectors in the transmission of preventable illness to vulnerable populations. Work in disability studies similarly centers on the relationship between rights, agency, identity, and the state (Kafer 2013, Wong 2020, Schalk 2022, Thrasher 2023). The contestations over institutional and community identity stories—how the state identifies you and how you understand yourself—become a central site of the politics of disease and identity.

Joanna Wuest notes in her 2023 book *Born this Way: Science, Citizenship, and Inequality in the LGBTQ+ Movement:* “We ought to be cognizant about how the desire ‘to know’ is textured by our circumstances” (Wuest 2023, 205). The history of modern sexual identity has always been tied to the production of scientific knowledge about difference and variation from the norm of the dominant classes. From Troy Duster’s call against genetic essentialism to Wuest’s critique that the LGBTQ+ movement regularly employs science to justify queer existence, the message is clear: science is a form of politics. No appeal to science or technology alone will necessarily change how our bodies are ordered. For these scholars, identity operates as the infrastructure for structured inequalities and an important basis for resistance. Risk is understood as a social condition, not a result of behavior or agency alone. The state uses identity stories to reverse that emphasis and insist that the only solution available is individual rather than collective.

In what follows, I use the establishment of the AIDS case definition to interrogate these institutional practices of identification and briefly explore the resistance and transformation of the technical case definition of AIDS to think through our current crisis. The literature reviewed in this section operates as a counter-narrative to the identity stories produced by the CDC. I demonstrate in the next sections that notions of equity, care, and community established by these HIV/AIDS activists, communities, and scholars were built out of resistance to the biased and destructive practices of institutional identity stories in the first decade of the pandemic. This history helps us to understand the choices available to us as LC becomes embedded in our institutions.

A Problem with Many Names

> "In the period of October-May 1981, 5 young men, all active homosexuals were treated for biopsy-confirmed Pneumocystis carinii pneumonia at 3 different hospitals in Los Angeles California. Two patients died. All 5 patients had laboratory confirmed previous or current cytomegalovirus (CMV) infection and candida mucosal infection."
>
> -Morbidity and Mortality Weekly Report, CDC, June 5, 1981

Congress tasks the Centers for Disease Control to release the latest data from state health departments and practicing physicians to report the normal and abnormal ways in which people in the U.S. die each week. This network of federal and state officials, bureaucrats, administrators, scientists, and doctors acts as the nation's warning system for new biological threats, outbreaks, and potential epidemics. The weekly reports compile and assemble associations, clues, symptoms, evidence, hunches, hypotheses, biases, stereotypes, and identities into official guidelines—which identify a problem and target populations to intervene upon and disseminate the latest known information about a possible threat. On June 5th, 1981, the CDC reported a strange pneumonia affecting young gay men, proving to be fatal, within the same metropolitan area. A new problem was identified, a target population was isolated, the U.S. Government's official discourse on AIDS was inaugurated, and the creation of a hybrid-identity story connecting gay men to AIDS began the process of becoming institutionalized.

James Curran, the spokesperson for the CDC at the time, was quoted in the *New York Times*: “Dr. Curran said there was no apparent danger to nonhomosexuals from contagion. ‘The best evidence against contagion,’ he said, ‘is that no cases have been reported to date outside the homosexual community or in women’” (Altman 1981). The connections made at this early stage consisted of similarities between people infected and diseases that were far from ordinary in patients of their background. Implicitly, the cause was “active homosexuality.” One of AIDS’ first and most persistent identity stories is established, and much of the politics and writing about institutions on this matter center on this moment—or seek to transform the norms, rules, and associations produced in this initial framing of the epidemic.

While Curran is unambiguous about the lack of a threat to “nonhomosexuals,” the CDC report he references, published the next day, is far less certain about the potential risks of the new disease:

> Although it is not certain that the increase in KS [Kaposi’s sarcoma] and PC [*Pneumocystis carinii]* is restricted to homosexual men, the vast majority of recent cases have been reported from this group. (MMWR July 3, 1981)

At this point, the CDC was only reporting forty-one total cases. The associations cemented into the social understanding of the disease carried on despite increasing evidence from the MMWR reports that AIDS could spread in several different ways (Epstein 1996, 47). While the focus would remain on gay men, the CDC’s reporting began to paint a picture of a disease that was rapidly jumping outside the confines of its official designations and definitions. This is one of the first indications that the association with gay men was seen as pragmatic rather than scientific, despite the data showing it was sexual activity, not identity, that put one at risk.

During this period, the CDC referred to the illness as Kaposi's sarcoma (KS), *Pneumocystis carinii* (PC), or opportunistic infections (OOI). From June of 1981 until the first report that used the acronym AIDS in September of 1982, the CDC released ten articles in the MMWR concerning the syndrome we now call AIDS. Within those ten articles, six referred to homosexual men only (MMWR 1981: June 5, July 3, Aug 28, 1982: May 21, June 4, June 8); one referred to people with hemophilia (MMWR 1982: July 16); one referred to Haitians (MMWR 1982: July 9); and two were broader in their focus (previously healthy persons, and a vaccine safety report) (MMWR 1982: June 11, Sept. 3). While the CDC was following the cases as they were being reported, data steadily began to show the virus emerging in populations outside of gay men.

At the same time, news reports and medical journals across the country offered an array of names for the new epidemic. *The New England Journal of Medicine* referred to the disease on December 10, 1981, as "Community-Acquired Pneumocystis" (Masur et al., 1981); two days later, *The Lancet*, a British medical journal called the disease "Gay Compromise Syndrome" (Brennan and Durak 1981). Newspapers similarly created their own names based on reporting from both the medical community and the growing activist community within gay populations. On April 16, 1982, the gay newspaper *The Washington Blade* referred to the disease as a "Gay Cancer;" on May 11, 1982, *The New York Times* referred to the increasingly popular Gay Related Immune Deficiency (GRID);" (Altman 1982), and on

August 9, 1982, the *Philadelphia Daily News* described the epidemic as a “Gay Plague” (Mckeown 1982).

In only a year, it became clear to the CDC Task Force on Kaposi’s sarcoma and other opportunistic infections that they must establish an institutional name to end the proliferation of confusing and inaccurate terms. In the summer of 1982, the CDC Task Force officially named the disease acquired immunodeficiency syndrome after a series of meetings with gay activists and hemophiliacs (Grmek 1990, 13). The acronym was an administrative choice, a bureaucratic solution to an increasingly complex problem of identification. The boundaries of the disease kept changing, and the CDC was attempting to highlight the populations most at risk and, at the same time, look at where the virus was traveling.

In the September 24, 1982, issue of the MMWR, the acronym AIDS is used for the first time along with surveillance data for the most at-risk populations:

> Reported AIDS cases may be separated into groups based on these risk factors: homosexual or bisexual males—75%, intravenous drug users with no history of male homosexual activity—13%, Haitians with neither a history of homosexuality nor a history of intravenous drug abuse—6%, persons with hemophilia A who were not Haitians, homosexuals, or intravenous drug abusers—0.3%, and persons of other groups—5%. (MMWR Sept. 25, 1982)

These four risky populations, “homosexuals,” heroin users, Haitians, and hemophiliacs, were increasingly referred to with the apocalyptic nickname of the “four H’s.” What is striking about this list of populations is how different they are in terms of organization. Groups are defined variously through their sexuality, behavior, nationality, a blood disorder, and “persons of other groups." This cycle of objectification and institutionalization, from GRID to AIDS, sets the conditions for future contestations about who gets resources, who is identified as "at risk," and how the epidemic is understood more broadly throughout the country. The four Hs became the first draft of the identity stories that would be contested over the next decade.

Within a year, AIDS had a name but was still spectral, borderless, and difficult to discern. The September 24th MMWR goes into extensive detail regarding the official guidelines for the diagnosis of AIDS in an editorial note:

> CDC defines a case of AIDS as a disease, at least moderately predictive of a defect in cell-mediated immunity, occurring in a person with no known cause for diminished resistance to that disease. Such diseases include KS, PCP, and serious OOI. Diagnoses are considered fit to the case definition only if based on sufficiently reliable methods…However, this case definition may not include the full spectrum of AIDS manifestations…conversely, some patients are considered AIDS cases on the basis of diseases only moderately predictive of cellular immunodeficiency may not actually be immune deficient and may not be part of the current epidemic. Absence of a reliable, inexpensive, widely available test for AIDS, however, may make the working case definition the best currently available for incidence of monitoring (MMWR Sept 24,1982).

The working case definition is designed to provide a surveillance and monitoring tool in the absence of an AIDS test, which would not be developed until 1985 with the discovery of HIV. Despite the neutral language of the case definition and no mention of sexual identity or the four Hs, this case definition reproduces the bias of the CDC's initial focus on gay men with access to healthcare. The diseases, symptoms, and all the "scientific" data used to derive this general definition came predominately from the

CDC's work with gay men. Absent a "…reliable, inexpensive, widely available test for AIDS" and the complex variation between cases meant that the association between gay sex and the syndrome became the pragmatic way for the CDC to monitor the disease and thereby cemented that association into the institutional response to AIDS.

AIDS, the acronym, was designed to move away from the sole association of the crisis with gay men; however, it was built by using data from gay men. The opportunistic infections listed in the definition were not the same infections and illnesses that women were experiencing, pushing women outside the bounds of the definition—even with this new neutral language. The naming and defining of AIDS creates what political science calls "path dependency" within HIV/AIDS policy, meaning its constituent terms became intractable and difficult to countermand once set in place. These institutional choices thereby reified and reproduced these identity stories about what it means to be HIV positive, who is at risk, and what types of intervention strategies are possible. While many of these imperatives have changed with HIV/AIDS politics, these changes primarily came through resistance to the institutionalizing of these identity stories from social movement actors. The AIDS case definition, then ironically, further cemented the notion that AIDS was a gay disease because it reflected the biased epidemiological work of the CDC.

There was clear evidence and research at the time that presented a different path for HIV/AIDS research and policy. In 1988, Dr. Joyce Wallace, a researcher who worked with AIDS patients, noted in an interview with the Gay Men's Health Crisis that it is a contingent historical fact that AIDS was first discovered in the gay community, "…so if people say women don't give it to men cause there's so few numbers, we have to remember the fluke that in this country AIDS started in homosexual men and in drug users." (Wallace 1988). Wallace understood that even if the epidemic started within one community, it would spread to women because it was transmitted through sexual intercourse. Sexual activity, not sexuality, allowed for HIV transmission. She understood immediately the danger that AIDS posed to populations of women who engaged in sex work and intravenous drug use, women in poverty, and women who were outside the realm of interagency reporting. These were women who did not have the access to medical care that some white gay men had in New York City.

Curran remembers an intense focus on gay men structuring the initial state response where there were concentrated populations of openly gay men (Curran 1998). While the CDC's epidemiological teams focused on gay men and those who encountered the public health system, Dr. Wallace was asking the NYC Board of Health to start looking directly at sex workers. She began seeing the first cases in sex workers and soon won a $25,000 grant to study women who engaged in anal sex (Wallace 1988). She showed earlier than the CDC and NIH that sex workers, in general, and women living in poverty, in particular, were at high risk for this disease, in no small part because they were the same population *least* likely to be captured by the CDC's reporting and research methods. It is less surprising then that the CDC's case definition of AIDS would leave out the opportunistic infections and cancers particular to women with HIV. Their stories, out of the surveillance apparatus of the CDC, were not objectified or institutionalized. Despite the CDC's data that women were vulnerable to the virus.

In 1988, Terry McGovern started working as a lawyer in Hell's Kitchen for the National Poverty Index. She began seeing an increasing number of people with HIV facing discrimination from the NYS Housing Authority, the Social Security Administration, and in prisons who had developed AIDS but did not fall within the case definition. This led her to start the HIV Law Project in 1989 to focus specifically on the needs of low-income people living with HIV. In 1990, McGovern filed a class-action lawsuit against the CDC on behalf of low-income people living with HIV but not diagnosed with AIDS. She worked with the AIDS Coalition to Unleash Power (ACT UP) consistently, and they funded and facilitated actions against the CDC and NIH, helping to connect different activist, medical, and legal coalitions. It would take a combined effort lasting over three years, the election of a Democratic president, and numerous meetings at the CDC before the official case definition was expanded. In November 1994, the CDC expanded the case definition to include anyone whose CD4+ cell count went below 200, and they added three new illnesses to the list of AIDS-defining illnesses: cervical cancer, recurrent bacterial pneumonia, and pulmonary Tuberculosis (McGovern and Smith 1998).

Women’s omission from the case definition would only be rectified 12 years into the epidemic by the pressure of a lawsuit, the support of a social movement apparatus, and the creative activism that spawned one of the period’s most hauntingly powerful activist slogans: “Women don’t get AIDS, they just die from it” (Day 2023).

This struggle of defining, naming, contesting, and redefining had tremendous material consequences on the lives of people living with HIV, particularly outside of systems of healthcare and support. This history shows identity stories' persistence in policy, research, activism, and politics. Naming which populations are vulnerable is a political act; it is not merely descriptive or diagnostic. Scientific observation and description aim to be objective, but this is merely the performance of objectivity that belies the way scientific institutions are always already structured within larger systems of funding, research, politics, and history.

Women were now included in the case definition, yet the inequalities of HIV did not stop once the case definition became more accurate. The definition allowed women to be diagnosed with AIDS and, at the same time, naturalized the idea that this virus was caused by risky behavior and that people suffering from HIV were personally responsible for a communicable illness. What changed is that poor women were now “at-risk” populations and a hybrid identity was established. You cannot get HIV alone, but the effects of this process of objectifying these identity stories lead to the notion that diseases are caused and cured through individual action. The conditions that make LC possible are based on these same notions of our bodies, the state, and disease management.

The Long-COVID Definition

In 2024, the National Academies of Sciences, Engineering, and Medicine released a consensus report that set out to define LC. They define LC as follows:

> Long-COVID (LC) is an infection-associated chronic condition (IACC) that occurs after SARS-CoV-2 infection and is present for at least 3 months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems (NASEM 2024).

On its face, this is a descriptive diagnostic tool. However, this definition belies deeper contestations about how the state will manage the next stages of the pandemic as COVID-19 becomes endemic in multiple forms. Beyond the facets of the definition that include the symptoms and the techniques for diagnosis this definition is unique because of its extensive focus on equity.

NASEM notes that they “found no published, standardized guidelines for developing disease definitions” and, therefore, defined their own standards based on similar diseases like HIV. They state that their working definition “…should be revised as new evidence emerged…this is in line with lessons from defining other diseases such as HIV/AIDS, which took years and multiple iterations to refine” (Ibid, 10). These aspirations are clearly and directly derived from the contestations surrounding HIV/AIDS.

However, the efforts to prevent the mistakes of past definitions lead to new missteps in this cycle of objectification of identity stories. In the section of the case definition devoted to the notion of equity, this comes into full relief:

> Equity needs to be considered at multiple steps in a LC patient’s journey to obtain care and services. [A] LC diagnosis may be considered regardless of health status, vaccination history, or demographics. This definition applies to both adult and pediatric patients. Socioeconomic factors, inequality, discrimination (based on race and gender, among others), bias, and stigma affect whether patients can receive a diagnosis and benefit from LC-targeted health care or services (Ibid, 9).

This definition of a drastically different illness than HIV reifies a similar process to what happened with the early history of HIV. As before, inequality becomes a description of the environment that individuals must traverse rather than understanding these structured inequalities as vectors of the disease itself. Here, equity is focused on being included in the case definition rather than in the healthcare system.

A key lesson to be learned from the AIDS epidemic in relation to LC is that the only way to make the definition, diagnosis, and treatment of LC equitable is through universal healthcare access and robust public health preventative measures. The repercussions of the inaccurate AIDS case description had long-lasting effects on HIV communities and healthcare policy. Managing disease and containing risk became central drivers in health policy. Even when the definition was reformed to include women, that in and of itself did not lead to longer lives and better outcomes for women without access to care. The consequences of institutional failure are far greater when case definitions determine who does and does not receive healthcare. If millions of people cannot access the care and resources to receive an LC diagnosis in the first place, then it is not sufficient for the state to define health equity as merely not discriminating against people in the diagnoses of the disease

It is difficult not to see HIV/AIDS identity stories, their contestations, and reformulations cycling through the working definition of LC despite the significant differences in the biology, transmission, and treatment of the two pandemics. The nod toward equity in the definition is a significant victory of institutional reform and change caused by generations of activism, organizing, and scholarship on HIV/AIDS. However, at the same time, as this institution adapts its work to include the language of equity, it hides the ways that these same institutions contribute to the structured inequality of our lives. Simple institutional tools like naming and defining have tremendous consequences regarding access to care, treatment, and prevention—and, consequently, set limits on individual agency.

Defining LC: Deciding the Future

“Disabled, immunocompromised, and chronically ill people know fully well that the world is not designed for us and how we are often dehumanized and considered burdens by the medical industrial complex. It is an exhausting struggle to be seen and heard while fighting to survive in the face of systemic oppression.”

-Alice Wong, Disability Visibility Project, 2024

This paper revisited the emergence of the case definition of HIV/AIDS to think through the current moment of defining our life with COVID-19. New hybrid identities are being produced through the objectification and institutionalization of these identity stories; HIV is but one example. These stories are central to scientifically producing knowledge about our bodies, identities, and communities. In the case of the first years of AIDS, these identity stories hinged on assembled relationships between queerness, drug use, blood, semen, sex, gender, migration, and a virus. These hybrid identities, in the case of HIV/AIDS, proved to be tremendously powerful in resisting and transforming the science, narratives, and policy of HIV. Understanding this history can help us make sense of the ways knowledge is being produced, proliferated, and used by the state in our current moment. From the rise of the term “essential workers” to anti-mask and anti-vaccine politics becoming mainstream, people understand their identity in relation to scientific discourse organized around bodies and risks.

Disability activist and author Alice Wong has spent the pandemic building the Disability Visibility Project, writing and chronicling her experience as a disabled person navigating the pandemic, forced to continue to live in quarantine as the majority of people “moved on” because of the collective decisions we have made about our shared responsibility to each other. Her writing and activism demonstrate how normalizing the pandemic by doing away with masks and preventative measures, coupled with the rise of anti-science politics, renders disabled people expendable. It is no surprise, then, that disability activists, HIV/AIDS groups, and anti-racist organizations have led the way in resisting the institutionalization of the first wave of COVID-19 identity stories. The decisions made throughout the first years of COVID have led to a world where masking, vaccines, and drug patents are all sites of contestation rooted in language. Sites of meaning-making, knowledge-production, and politics in the banal, everyday decisions of naming, defining, and categorizing,

The minutia of scientific institutions developing definitions, naming, and describing the microscopic world significantly influence the organization of our lives. Employing Hayward's framework helps us to see how identity stories are embedded within institutional practices, leading to path dependencies in U.S. health policy. The history of HIV/AIDS not only demonstrates how difficult it is to dislodge these dependencies from our policy imperatives; it also provides theories, tools, and options to resist these inequalities. Furthermore, the history of HIV/AIDS activism and scholarship challenges institutional notions of equity offered in response to LC. To read this history in our present moment offers a different set of politics focused on the material reality of living with diseases. This politics centers on notions of equity that are based on access to care and treatment, harm reduction, ending the criminalization of sickness, and combating stigma and discrimination that poor and marginalized communities too often face. Understanding how institutions conceptualize equity is an important step in transforming these definitions to match the lived experience of people living with LC and moving towards more just systems of care. The case definition of LC offers new fronts to practice such politics as the definition and the syndrome become embedded in our institutions, laws, and lives.

References

Altman, Lawrence K. 1981. "Rare Cancer Seen in 41 Homosexuals." *New York Times*, July 3, 1981.

_____ 1982. "NEW HOMOSEXUAL DISORDER WORRIES HEALTH OFFICIALS." *The New York Times*. May 10. http://www.nytimes.com/1982/05/11/science/new-homosexual-disorder-worries-health-officials.html.

Brennan, Roberto., and Davidt. Durack. 1981. "Gay Compromise Syndrome." *The Lancet* 318 (8259): 1338–39.

Brier, Jennifer. 2011. *Infectious Ideas US Political Responses to the AIDS Crisis.* Chapel Hill (N.C.): University of North Carolina Press.

Centers for Disease Control. Morbidity and Mortality Weekly Reports (MMWR):

"Pneumocystis pneumonia-Los Angeles." MMWR 1981 June 5; 30:250-2.

"Kaposi's sarcoma and Pneumocystis pneumonia among homosexual men—New York City and California." MMWR 1981 July 3:30: 305-8.

"Follow-up on Kaposi's Sarcoma and pneumocystis pneumonia" MMWR 1981 Aug 28; 30:409-10

"Persistent, generalized lymphadenopathy among homosexual males" MMWR 1982 May 21: 31:249-52

"Diffuse, undifferentiated non-Hodgkin's lymphoma among homosexual males—United States" MMWR 1982 June 4; 31:277-79.

"Update on Kaposi's sarcoma and opportunistic infections in previously healthy persons—United States" MMWR 1982 June 11; 31: 294-301.

"A cluster of Kaposi sarcoma and *Pneumocystis carinii* pneumonia among homosexual male residents of Los Angeles and Orange Counties, California" MMWR 1982 June 18; 31:305-7.

"Opportunistic infections and Kaposi's sarcoma among Haitians in the United States" MMWR 1982 July 9; 31: 353-61

"*Pneumocystis carinii* pneumonia among persons with hemophilia A." MMWR 1982 July 16; 31: 365-7

"Hepatitis B virus vaccine safety: report of an inter-agency group." MMWR 1982 Sept 3; 31:465-67

"Update on Acquire Immune Deficiency Syndrome (AIDS)—United States" MMWR 1982 September 24: 31: 507-14.

"Acquired Immunodeficiency syndrome (AIDS) update—United States" MMWR 1982 June 24; 32: 309-11.

MMWR Surveillance Summaries, "Distribution of AIDS cases by Racial/Ethnic Group Exposure Category, United States" Vol 37. No. SS-3, June 1, 1981-July 4, 1988. p 1-10.

MMWR Surveillance Summaries, "Surveillance for AIDS and HIV Infection Among Black and Hispanic Children and Women of Childbearing Age, 1981-1989." Vol 39, No. SS-3, pp. 23-30.

"Revised Surveillance Case Definition for HIV Infection." MMWR 2014 April 11; 63: 1-10

Centers for Disease Control. 2011. "30 Years of HIV in African American Communities: A Timeline." *Http://Www.cdc.gov/Nchhstp/Newsroom/Docs/Timeline-30years-Hiv-African-American-Community-508.Pdf*.

Centers for Disease Control. 2024 "LC Basics" https://www.cdc.gov/COVID/long-term-effects/index.html.

Cohen, Cathy J. 1999. The Boundaries of Blackness: AIDS and the Breakdown of Black Politics. Chicago: University of Chicago Press.

Curran, James. 1998 interview by Victoria Harden, National Institutes of Health Office of NIH History, "In Their Own Words: NIH Researchers Recall the Early Days of AIDS." May 19.

Day, Emma 2023. *In Her Hands: Women's Fight Against AIDS in the United States*. Oakland: University of California Press.

Duster, Troy. 1990*. Backdoor to Eugenics*. New York: Routledge.

Epstein, Steven. 1996. *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley: University of California Press.

Geary, Adam M. 2014. *Anti-Black Racism and the AIDS Epidemic: State Intimacies.* New York, NY: Palgrave Macmillan.

Gilman, Sander L. 1987. "AIDS and Syphilis: The Iconography of Disease." *October* 43: 87. doi:10.2307/3397566.

Grmek, Mirko D. 1990. *History of AIDS: Emergence and Origin of a Modern Pandemic*. Princeton, NJ: Princeton University Press.

Hayward, Clarissa Rile. 2013. *How Americans Make Race: Stories, Institutions, Spaces*. New York: Cambridge University Press.

"History of AIDS Up to 1986." 2014. *HIV and AIDS Information and Resources*. Accessed May 23. http://www.avert.org/history-aids-1986.htm#footnote14_6a22afm.

Hoppe, Trevor. 2018. *Punishing Disease: HIV and the Criminalization of Sickness.* Oakland, CA: University of California Press.

Juhasz, Alexandra and Theodore Kerr. 2022. *We Are Having this Conversation: The Time of AIDS Cultural Production*. Durham, NC: Duke University Press.

Kafer, Alison, 2013. *Feminist, Queer, Crip*. Indiana University Press.

Masur, Henry, Mary Ann Michelis, Jeffrey B. Greene, Ida Onorato, Robert A. Vande Stouwe, Robert S. Holzman, Gary Wormser, et al. 1981. "An Outbreak of Community-Acquired Pneumonia." *New England Journal of Medicine* 305 (24): 1431–38. doi:10.1056/NEJM198112103052402.

McClelland, Alexander 2024, *Criminalized Lives: HIV and Legal Violence*. Rutgers University Press.

McKay, Richard. 2017. *Patient Zero and the Making of the AIDS Epidemic*, Chicago: University of Chicago Press.

McKeown P. 1982. ''Gay Plague' Baffling Medical Detectives', Philadelphia Daily News, August 9

McGovern, Theresa 2007, interview by Sarah Schulman, The ACT-UP Oral History Project, May 25.

McGovern, Theresa, and Raymond A Smith. 1998. “AIDS, Case Definition Of.” *TheBody.com*. http://www.thebody.com/content/art14002.html.

National Academies of Sciences, Engineering, and Medicine. 2024. A LC Definition: A Chronic, Systemic Disease State with Profound Consequences. Washington, DC: The National Academies Press. https://doi.org/10.17226/27768.

National Institute of Allergy and Infectious Diseases. 2024 “Decades in the Making: mRNA COVID-19 Vaccines” April 4. https://www.niaid.nih.gov/diseases-conditions/decades-making-mrna-COVID-19-vaccines

Pitchenik, Arthur E., Margaret Fischl, Gordon Dickinson, Daniel Becker, Arthur Fournier, Mark O'Connell, Robert Colton, and Thomas Spira. 1983. “Opportunistic Infections and Kaposi's Sarcoma Among Haitians: Evidence of a New Acquired Immunodeficiency State.”

Annals of Internal Medicine 98 (3): 277–84. doi:10.7326/0003-4819-98-3-277.

Renfro, Paul M. 2024 *The Life and Death of Ryan White: AIDS and Inequality in America.* Chapel Hill: University of North Carolina Press.

Resnik, Susan. 1999. *Blood Saga: Hemophilia, AIDS, and the Survival of a Community*. Berkeley: University of California Press.

Schalk, Sami 2022. *Black Disability Politics*. Duke University Press.

Schulman, Sarah. 2021 *Let the Record Show: A Political History of ACT UP New York, 1987-1993*. Farrar, Straus & Giroux.

Somerville, Siobhan B. 1994, “Scientific Racism and the Emergence of the Homosexual Body.” *Journal of the History of Sexuality*, Vol. 5 No 2. (October), pp. 243-266.

_____ 2000. *Queering the Color Line: Race and the Invention of Homosexuality in American Culture*. Durham: Duke UP.

Stanley, Eric A and Nat Smith 2015. *Captive Genders: Trans Embodiment and the Prison Industrial Complex*. Second Edition. AK Press.

Thrasher, Steven W. 2023 *The Viral Underclass: The Human Toll When Inequality and Disease Collide*. McMillan Press.

Treichler, Paula A. 1999. *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS*. Durham: Duke University Press.

_____ 1987. “AIDS, Homophobia, and Biomedical Discourse: An Epidemic of Signification.” *Cultural Studies* 1 (3): 263-305.

Wallace, Joyce 1988 interview by Gay Men’s Health Crisis, Gay Men’s Health Crisis records 1982- 1999, video file 7635.mp4, New York Public Library Manuscripts and Archives Division, April 15.

Wong, Alice, 2024. “#N95s4UCSFL Call to Action.” Disability Visibility Project. January 25. https://disabilityvisibilityproject.com/2024/01/25/n95s4ucsf-call-to-action/

_____ 2020. *Disability Visibility: First-Person Stories from the Twenty-First Century*. Vintage.

World Health Organization. 2013. “Women's Health.” *World Health Organization*. September 30. http://www.who.int/news-room/fact-sheets/detail/women-s-health.

UNAIDS. 2022. “20.2 Million Girls and Women Are Living With HIV” March 8. https://www.unaids.org/en/resources/infographics/girls-and-women-living-with-HIV