



AIDS: A Cultural History Professor Joanna Bourke

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Between 25 and 40 million people worldwide have died as a result of opportunistic infections arising from AIDS or Acquired Immunodeficiency Syndrome. It may seem obscene, therefore, to claim that knowledge about AIDS has always been refracted through images, symbols, and other forms of representation. For people *living* with HIV, *dying* of AIDS, and *witnessing* as well as *grieving* dissolution and death, suffering is complex and embodied. Nevertheless, the 'war on HIV/AIDS' (and I will be problematizing the use of military metaphors shortly) has remained relentlessly representational.

This is why I want to begin this talk by looking at one image. (See <https://emuseum.mfah.org/objects/70048/tom-moran-boston-mass>.) This is Tom Moran, a 37-year-old physical therapist who grew up in a large Catholic family in the southern suburb of Quincy, outside Boston. The photograph was taken by Nicholas Nixon, shortly before Moran died on 8th February 1988. It is part of a series of portraits of 'People with AIDS', tracing the devastating impact of AIDS on the bodies of men and women (of whom there were four) over several months. Nixon claimed that he sought to 'humanize the disease, to make it a little bit less something that people see at arm's length'. He hoped that his photographs would 'add[] an extra dimension to the fact of the illness and help[] people understand that it is just a virus and could hit any of us'.

What do you see when you look at the photograph of Tom Moran shortly before he died?

Dixon's photographs of Tom Moran and the other desperately ill people divided opinions. In *Artforum*, photographer Charles Hagen contended that the power of Nixon's 'People with AIDS' photographs 'stems in part from our inherent horror and fascination with the decay of the flesh'. The photographs 'allows us intimacy, even allows us to stare cruelly, in our effort to comprehend the nature of physical existence and, by extension, of death'. Hagen observed that

"what is usually lacking in all of the media uproar about AIDS... is a sense of the victims as something more than cases, anonymous components of statistics. It is precisely their identity as individuals that the society denies them, because many of them are outsiders — gay people or drug users. This quality of otherness, which is imposed on them whether or not they are sick, allows the culture to treat the destruction the disease causes as just another moral fiction, not a human event."

In contrast, Hagen contended, Nixon

"never treats the AIDS patients he photographs as cases or specimens to be examined dispassionately, at a distance. His final photograph of Tom Moran is a close-up (so that in print he appears life-size); Moran looks at the camera, and through it at us. This is a human being, not a statistic, not a convenient object for moral judgment."

Nixon not only 'insists on the individuality of the people he depicts' but also, by creating a sense of 'intimacy', allows viewers to 'recognize the terrible truth of their suffering'.

But lots of people who saw the photographs strongly disagreed – and, most importantly, many of those people protesting the photographic depictions of 'People with AIDS' were those who were also witnessing

the deaths of friends and lovers, as well as struggling with the emotional and physical consequences of their own HIV diagnoses.

The most trenchant of these complaints was made by Douglas Crimp, an activist in ACT UP (AIDS Coalition to Unleash Power), founded in 1987. Crimp was appalled that Nixon was reproducing highly damaging tropes. The photographs not only portrayed people with AIDS as isolated individuals (where were their lovers, friends, and comrades?) but were also frightening entire communities. The photographs showed people 'ravaged, disfigured, and debilitated by the syndrome; they are generally alone, desperate, but resigned to their "inevitable" deaths'. The photos lacked all political context. Rather than provoking empathetic responses, the photographs encouraged viewers to recoil in disgust and alarm. In Crimp's words, the photographs

"could produce a phobic effect in which the last thing one would ever want to do would be to identify with their subjects. A viewer could see them neither as human nor as possible self-images, but rather as images of abjection and otherness."

Crimp also castigated Nixon for failing to demonstrate his own empathy. He quoted Nixon's comments about another man he photographed for 'People with AIDS', Tony Mastrorilli. Crimp complained that Mastrorilli was

"giving me a blank wall. He was saying '... I don't like this process, I don't like this big camera, I don't like it close to me, I don't like cooperating with you.... I'm uncomfortable.' But at the same time[,] he kept on going through the motions. I had to drive forty minutes to his house. I'm not interested in somebody just going through the motions. Life's too short."

– by which Nixon meant *his* life (that is, Nixon's). In other words, Crimp detected a failure on Nixon's part to focus on the *patient's* needs rather than the *artist's* desires for a 'good' photograph. This was part of what many ACT UP activists saw as the depoliticization of AIDS portraiture. It was a comment echoed by Simon Watney, British AIDS activist and cofounder of Outrage!, which campaigned for lesbian and gay rights between 1990 and 2011. Watney was outraged by the fact that photographs such as the ones by Nixon 'abstract the experience of people living with AIDS away from the determining context of the major institutions of health care provision and state'. They 'repeatedly individualized' the syndrome, thus 'subtly and efficiently de-politiciz[ing]' it. As I quoted Nixon saying earlier, he hoped that his photographs would 'help[] people understand that it is just a virus and could hit any of us' – a comment that ignores wide disparities of suffering, caused by inequalities, discrimination, and political 'othering', as we shall see shortly.

But first: Let's take a few steps back, in order to trace the history of a virus that was to define the *late*-twentieth century in a similar way to the polio virus epidemics of the *mid*-twentieth century, which I explored in an earlier lecture in this series. The story I am going to tell is largely focused on the U.S. and Britain, because those are the regions of my expertise, but I will be periodically reminding us of the global dimension.

Forty-two years ago, on 5 June 1981, the U.S. Centers for Disease Control and Prevention (CDC) registered the appearance of a previously rare form of pneumonia in five gay men in Los Angeles. A month later, the CDC's *Morbidity and Mortality Report* noted that 26 young gay men from New York had presented with Kaposi Sarcoma. Before the end of that year, public health experts were warning of an epidemic of illness among gay men and intravenous drug users. Although initially labelled 'gay cancer' then 'Gay Related Immune-Deficiency' (GRID), by the summer of 1982, it had been named 'Acquired Immunodeficiency Syndrome' (AIDS). In 1983, the human immunodeficiency virus (HIV) was identified, leading Robert Gallo (the virologist who co-discovered the virus while working at the National Institute of Health) to predict that a vaccine could be found within a couple of years. It took another two years to invent a test that could identify the virus, an important step because otherwise the virus to remain undetected for up to a decade.

By 1985, a panic was underway, with *Life* magazine running a cover in July that year announcing that 'Now No One is Safe from AIDS'. It was an invidious headline, subtly conveying the view that homosexuality was not only a lethal disease, but it was also contagious. The headline also implied a distinction between 'innocent' and 'guilty' people suffering from HIV/AIDS. The former included children, heterosexuals, and haemophiliacs; the latter were gay men and intravenous drug users. The poster boy for distinguishing 'innocent' sufferers was Ryan White, a haemophiliac who acquired HIV through a contaminated factor VIII

blood treatment, was diagnosed with AIDS in December 1984, and died in 1990 just one month before his High School graduation. The ‘everyone’ on *Life* magazine’s cover eventually included actor Rock Hudson (diagnosed in 1984), NBA star Magic Johnson (1991), and tennis hero Arthur Ashe (1992). By the time of their illnesses becoming known, 15,000 Americans had been diagnosed as HIV-positive and nearly 13,000 had died of complications caused by AIDS. By 1994, AIDS had become the leading cause of death for Americans aged 25 to 44.

Certain communities suffered higher morbidity and mortality. Although the syndrome is typically represented in terms of white, homosexual, male populations, of the 355 cases of Kaposi Sarcoma and other AIDS-related infections reported in the medical literature in the year after June 1981, thirteen were heterosexual woman. Even a decade later, however, the CDC (Centers for Disease Control and Prevention) did not include in their case definition of AIDS the most common illness manifestations among women – that is, invasive cervical cancer and recurrent vaginal yeast infections. Women were also excluded from drug trials. This was despite the fact that, by 1990, AIDS was the leading cause of death for African American women. Today, 19 per cent of new HIV infections are among women, 54 per cent of whom are African American. 84 per cent were infected by the virus through heterosexual contact. The illness is also raced white, although 42 per cent of new infections reported in 2019 occurred amongst African-Americans, who are only 13 per cent of the U.S. population. Of African-Americans, Hispanics, and Latino/a contracting the infection that year, 56 per cent were engaged in male-to-male sexual contact. As we have seen throughout this series of lectures, these statistics are certainly underestimates: minoritized people’s illnesses and deaths often don’t ‘count’; and so are ‘uncounted’. Many poorer people also cannot afford Medicaid, dying before any diagnosis can be made.

Scientists struggled to find a way to halt infections. The first anti-retroviral drug to be approved was AZT, or azidothymidine, a nucleoside agent that inhibits the enzyme reverse transcriptase that the HIV virus uses to make DNA, therefore diminishing its ability to replicate. As a monotherapy, it proved inadequate since the virus built up resistance and mutated. A decade later, in 1996, virologist David Ho announced to a stunned audience at the 11th International AIDS conference in Vancouver that anti-retroviral drugs combined with protease inhibitors would fight off the virus. Almost overnight, HIV-positive people who could afford the drugs became chronic patients as opposed to people living out a death sentence. If diagnosed early and taken regularly, anti-retroviral (ART) medications are effective. This has become known as the ‘Lazarus syndrome’.

The drugs do have side effects, however: patients experience heightened risk of heart disease, lipodystrophy, and diarrhoea, as well as other long-term toxicities. Furthermore, people have to take very large quantities of the drugs their entire life (discontinuing the drugs causes the virus to be reactivated). As a result, researchers shifted their focus from prevention to ‘adherence’ – that is, behavioural studies about how to ensure that people with AIDS adhered to a strict regime of drug-taking. The drugs were made available in unequal ways. Regular usage was found to be challenging for people with less stable lives. The new technologies failed to take account of socio-political contexts in which these technologies circulated, including their costs and the need for punctuality. They ignored the disproportionate impact of homophobia, drug use, colonialism, and discrimination in employment, housing, and health care for certain groups. In 2012, a meta-analysis published in *The Lancet* found that HIV-positive Black ‘men-who-have-sex-with-men’ (MSM) were 22 per cent (Britain) to 60 per cent (U.S.) less likely than other HIV-positive MSM to receive combination anti-retroviral therapy. In the U.S., HIV-positive Black MSM were also less likely to have health insurance, adhere to anti-retroviral therapy, or be virally suppressed than other HIV-positive MSM. The *Lancet* researchers concluded that ‘Elimination of disparities in HIV infection in black MSM cannot be accomplished without addressing structural barriers or differences in HIV clinical care access and outcomes’.

HIV/AIDS came as a shock to populations who had come to believe that infectious epidemics were a ‘thing of the past’ and that the main public health issues were chronic diseases such as cancer and heart problems. The epidemic also came immediately after a period of optimism and pride for many gay individuals and communities. No-one doubted that homophobia was pervasive throughout the 1960s and 1970s, but there were reasons to be hopeful. For example, in the U.S., the Civil Rights Act of 1964 had outlawed discrimination based on sex as well as race, colour, and religion. In 1969, the Stonewall Uprising in Greenwich Village (lower Manhattan) served as a catalyst for gay, lesbian, and queer protest and pride. Throughout the 1960s and 1970s, sexual restrictions loosened; the counterculture was exploding; feminism was thriving. Human rights as well as the rights of the disabled and other minoritized groups were being championed. Medically, too, there was a mood of optimism, including an assumption that antibiotics had minimized the longer-term risks of contracting sexually transmitted infections. AIDS activist Michael Callen even bragged that, in his

pre-HIV life, he wore his 'STD's as red badges of courage in a war against a sex-negative society'. It was also made official: homosexuality was no longer a psychiatric disorder. In 1973, it was removed from the second edition of the Diagnostic and Statistical Manual of the American Psychiatric Association. By the mid-1970s, more than half of U.S. states had decriminalized homosexuality in private. In the main cities, vibrant, supportive, and proud communities of LGBTQ people became much more visible.

This mood of optimism was shattered in the 1980s. The HIV/AIDS epidemic both coincided with and fuelled a homophobic backlash. The trend towards increased acceptance of sexual difference was reversed. Metaphors that designated HIV/AIDS as "The Plague" (a virus wrecking a new Armageddon) and "The Bomb" (similar to the destructive possibilities inherent in the nuclear arsenal) helped to create hostile attitudes towards people with the virus. There were calls for the re-criminalization and re-medicalization of homosexuality. Homosexuals and 'queers' were blamed for the decline of the nuclear family and the rise of promiscuity. While in 1983, 62 per cent of British people polled thought homosexual relations were always to mostly wrong, by 1987, this had jumped to 74 per cent. The 2000s saw a shift to more acceptance (in 2000, the percentage of people who disapproved of homosexuality dropped to 46 per cent and then to under 30 per cent by 2010), but two decades of heightened homophobia had severely hampered medical research and treatment, while serving as a deliberate attack on the dignity for minoritized communities. LGBTQ+ people had long been denied 'moral citizenship'; the AIDS epidemic set them even further outside the fully-human, let alone any entitlement to be regarded as 'upstanding' citizens entitled to full human rights.

The ascendancy of conservative religious organisations boosted hostile attitudes. At the start of the HIV/AIDS crisis, the Catholic Church had taken a compassionate stance. An emphasis on the 'social gospel' meant a focus on the equality of all people under God, coupled with an urge to tackle the wrongs associated with poverty and discrimination. By the 1980s, however, a more conservative wing of the Church had come into power, obsessed less with social issues and more with morality, specifically the 'universal blessings' of heterosexuality and the monogamous family-unit. The Catholic Church's powerful stakes in health care, including hospitals and hospices, meant that their insistence that 'good morality is good science' (the phrase was used by Cardinal John O'Connor of New York) was especially damaging. In effect, 'deviants' were blamed for their own suffering. Religious organizations routinely claimed that the virus was a *moral* as much as a *medical* issue. It was God's punishment for sinful sexual behaviours, claimed evangelical televangelist Jerry Falwell. A 1986 Gallup poll revealed that 43 per cent of Americans believed that HIV/AIDS were 'divine punishment for moral decline'. For many people living with HIV/AIDS, rejection by their spiritual advisers and communities was particularly painful. The impact on dying people with AIDS could be devastating. Even those who had abandoned the religious views of their families might be terrified to be told that their 'lifestyle' was leading them straight into the fires of hell.

In the early years of the epidemic, a lack of knowledge about routes of transmission helped foster such hostile responses. Was AIDS passed in the air through breathing? Could it be spread through perspiration? If either of these were correct, then children like Ryan White, the haemophiliac who contracted the virus through blood treatment, should be prevented from attending school or, if allowed to attend, enclosed inside glass cubicles. Authorities abruptly shut down gay bathhouses and many gay community centres. If a person's diagnosis became known, they could be fired from their job, refused health insurance, and evicted from their homes. Immigrants faced huge stigma and incarceration, especially if Haitian. Restaurants who employed 'gay waiters' noticed a drop in the number of customers. In public facilities, toilet seats became objects of hysteria. In 1983, even Anthony Fauci (who, in Covid-years, has served as medical adviser to Presidents Donald Trump and Joe Biden) speculated in the *Journal of the American Medical Association* that 'routine household contact', such as sharing eating utensils could transmit HIV. As the person appointed Director of the National Institute of Allergy and Infectious Diseases, his comment that 'If routine close contact can spread the disease, AIDS takes on an entirely new dimension' was damaging.

Even after it had been established that the virus could only be transmitted through the exchange of bodily fluids, some medical professionals refused to treat people they suspected of being HIV-positive. Food trays were left outside hospital wards for desperately ill patients or their friends to collect. Some funeral parlours refused to bury people who they suspected of having died of AIDS complications. Parents sought 'respectability' over honesty about their loved one's life. Obituaries were coy in recording 'cause of death', euphemistically noting that a person 'died after a long fight with cancer'. The families of patients disregarded the preferences of their family members: they refused to allow partners, lovers, and carers to 'say goodbye' and then claimed ownership of any remaining financial resources such as property.

Politicians were particularly punitive in their responses. Some (such as Senator Jesse Helms) argued that infected people should be required to live in segregated housing facilities. Helms contended that ‘We have got to call a spade a spade, and a perverted human being a perverted human being’. In 1987, he was successful in proposing a budget amendment banning federal funding for HIV/AIDS initiatives that mentioned homosexuality. In March 1986, William F. Buckley (the conservative editor of the *National Review*) made the case that ‘everyone detected with AIDS should be tattooed [sic] in the upper forearm, to protect common-needle users, and on the buttocks, to prevent the victimization of other homosexuals’. William Bennet, who was Education Secretary, wanted prisoners who tested positive for HIV to be kept incarcerated even after the end of their sentences. Pat Buchanan, Communications Director for President Ronald Reagan, contended that AIDS was ‘nature’s revenge on gay men’. These were not isolated views. In California, a poll calling for mass quarantines collected almost 400,000 signatures. In 1985, 51 per cent of Americans supported quarantining people with AIDS, 51 per cent supported a law making it a crime for a person with AIDS to have sex with another person, nearly half approved of ID cards for those who tested positive for AIDS antibodies, 45 per cent supported testing job applicants for AIDS antibodies, and one in seven favoured tattooing those with the disease. Violence against gay men soared – in New York City between 1984 and 1987 alone, acts of violence against gay men jumped from 176 to 517.

Black communities experienced additional prejudices. Racists claimed that Black communities were ‘teeming’ with sexual deviants, drug addicts, and prostitutes. High levels of unemployment, homelessness, and incarceration fuelled racialized forms of homophobia. High levels of HIV amongst Black women confirmed long-standing xenophobic narratives about Black women as sexually promiscuous and transmitters of all kinds of sexually transmitted infections, especially syphilis.

In these contexts, misinformation spread widely. This was especially the case when it came to ‘safe sex’. And some advice was, frankly, ludicrous. Take physician Art Ulene, writing in *Safe Sex in a Dangerous World* (1987). He seriously argued that ‘its time to stop talking about “safe sex”. I believe we should be talking about safe partners instead’. He then contended that

“one way to find safer partners... is to move to a place where the incidence of AIDS is low. There are two states that have reported only four cases of AIDS since the disease was discovered, while others are crowded with AIDS patients.”

In other words, New Yorkers should flee to Nebraska! Adverts about the need to use condoms also generated some ridiculous advice. My favourite is when the president of the International Banana Association wrote a letter of complaint to the president of the Public Broadcasting Service (PBS). He complained that ‘the choice of a banana rather than some other inanimate prop’ in demonstrating how to put on a condom ‘constitutes arbitrary and reckless disregard for the unsavory association that will be drawn by the public and the damage to our industry that will result therefrom’!

Unsurprisingly, conspiracy theories spread like wildfire. Was HIV/AIDS caused by witchcraft or inadvertently offending ancestors? Was HIV a ‘man-made bio-weapon’ deliberately created and released by U.S. research laboratories or the CIA? Was it part of a plot to kill Black people? Actor and film director Spike Lee spread rumours that AIDS was ‘government-engineered disease’. He accused the authorities of making the mistake of thinking that the virus could ‘just be contained to the groups it was intended to wipe out’. But, ‘exactly like drugs’, it ‘escaped the urban centers into white suburbia’. Lee speculated that the day was ‘fast approaching when you want documented blood tests from prospective sexual partners. No papers, no sex’.

Some scientists even embraced conspiracy theories, claiming that governments, multinational corporations, and pharmaceutical companies were in league: they were refusing to investigate whether HIV was ‘really’ linked to AIDS, were lying to people about the toxic nature of anti-retrovirals, and were exaggerating the number of deaths. Virologist Peter Duesberg publicly argued that AIDS was not caused by the HIV virus (he offered to inject HIV into his own veins as proof) and warned that anti-retrovirals were simply a way to channel profits to major pharmaceutical companies. South Africa’s president Thabo Mbeki and members of his cabinet were converts. Mbeki’s Minister of Health, Manto Tshabalala-Msimang urged South Africans to spurn the ‘toxic’ ARV treatment and resort to ‘traditional’ remedies including garlic, beetroot, African potatoes, and lemon juice. This advice is believed to be responsible for the deaths of around 300,000 HIV-infected South Africans. Throughout the globe, AIDS deniers and ‘cultropreneurs’ (that is, entrepreneurs who disregard science, promote conspiracy theories, and seek to profit from ‘alternative’ remedies) have resulted in

devastating public health consequences.

Deadly prejudices were enflamed further in 1987 after Randy Shilts published *And the Band Played On*. As the first history of the syndrome, Shilts was persuaded by his publisher to sensationalise ‘Patient Zero’ (Gaëtan Dugas, a gay French-Canadian flight attendant) as the person who ‘brought AIDS to North America’. Dugas was diagnosed with cancer in May 1980 and died in March 1984. Shilt’s portrayal of Dugas was that of a one-dimensional, diabolical foreigner. For Shilts, Dugas was a psychopathic villain who could have stepped straight out of a gothic novel. *And the Band Played On* was the most widely read book on the ‘plague’ and became one of the most influential books of the time. This was despite the fact that even the designation ‘Patient Zero’ was wrong – it was a slip of the pen that transformed a CDC epidemiologist’s ‘O’ meaning ‘Outside of California’ for a zero (0), read as ‘Patient Zero’. Furthermore, as historian Richard A. McKay has shown in *Patient Zero and the Making of the AIDS Epidemic* (2017), nearly everything published about Dugas was inaccurate. Rather than an irresponsible spreader of death, Dugas was a charming, personally attractive, and proudly ‘out’ gay man, much loved by his family. At the time Dugas was diagnosed, little was known about how the virus was transmitted. The gay community had very good reason to be wary of the medical establishment and the way they moralized against homosexuality, contributed to homophobic rhetoric, and sought to monitor their communities. As Michael Lynch (founding member of AIDS Action Now!) warned, ‘We must challenge the medical profession whenever it attempts to regain its power to define us, or to cloak a moral programme in medical terms’. Throughout, Dugas accessed what evidence was available and acted accordingly, even participating in HIV support groups. As McKay observes, Dugas

“had received a cancer diagnosis in 1980, months before KS [Kaposi Sarcoma] was linked to the newly emergent syndrome that weakened patients’ immune systems.... After months of thinking of himself as a cancer patient, it seems plausible that he would have viewed with skepticism attempts to link his illness to cases of pneumonia and other infections affecting gay men.”

Dugas, along with a large section of the gay community (as we will see shortly) believed in the ‘overload’ theory of the disease as propagated by New York infectious diseases expert Joseph Sonnabend. This held that the disease was the result of the collapse of the immune system due to multiple partners: if people restricted their number of partners, their immune systems would recover. This was exactly what Dugas did. After contributing to the demonization of ‘Patient Zero’, Shilts himself died of AIDS in 1994.

Dugas’ name is routinely mentioned by people advocating the criminalization of virus transmission. He is the mythical, malicious criminal blamed for deliberately spreading infections. This made him a convenient scapegoat for politicians, policy makers, and public health officials seeking to introduce laws prosecuting people who fail to disclose their sero-positive status to their partners or who engage in behaviours that increase risk of transmission. The laws differ according to the jurisdiction but most did not criminalize *actual* transmission, but *potential* transmission; that is, the ‘victim’ in this ‘crime’ need not have contracted the virus at all. Although most of the laws refer only to sexual intercourse, some include oral sex, biting, spitting, or throwing bodily fluids, all actions where the risk of transmission is incredibly low or non-existent. As of 2020, criminal laws associated with HIV/AIDS had been passed in at least 72 nations (or 105 separate criminal jurisdictions, such as individual U.S. and Australian states). In the U.S., 29 U.S. states (led by Florida) have introduced HIV-specific laws and 24 states have prosecuted people living with HIV under general criminal laws. Conviction under these laws can result in lengthy prison sentences. In at least five states, people can be sentenced for up to twenty years while in another eighteen states this rises as high as ten years. In many jurisdictions, people who are convicted are required to register as sex offenders.

Canada is one of many countries that has particularly harsh laws associated with HIV transmission. From 1998, people living with HIV had a legal duty to disclose their viral status to sexual partners if sex posed a ‘significant risk’ of HIV transmission. In 2012, however, a judgement by the Supreme Court significantly broadened the rules. It ruled that people were required to tell a sexual partner if they had HIV before engaging in sex if there was a ‘realistic possibility’ of transmission. This means that unless a person has *both* a low viral load *and* wears a condom, their partner’s consent to sexual intercourse is considered to have been ‘vitiating’, leading the way to prosecutions for aggravated sexual assault. If convicted, people can be imprisoned (technically, this could mean a life-sentence with no chance of parole for 25 years) even if they were not infectious and there had been no transmission of HIV. The evidence shows that more than half of the cases in Canada that ended in conviction involved no HIV transmission. Of those convicted, 93 per cent received a prison sentence; in 72 per cent of cases, this was over two years.

Carceral responses to public health crises (which is also known as ‘public health governance through criminal law’) had been made necessary by the introduction and spread of neoliberal economic policies, resulting in severe reductions in social welfare, including public health. This turn to the carceral state was not new. Queer communities and other minoritized or ‘deviant’ groups (such as impoverished, unmarried mothers blamed for giving birth to ‘crack babies’) have a long history of persecution. As with other forms of health-related criminalization, it is counterproductive: by increasing the stigma associated with infection, people are discouraged from disclosing their status, let alone seeking treatment. This form of discrimination is particularly pernicious for sex workers, who are often sentenced to additional years in prison if they are found to be HIV-positive. It also disproportionately affects minoritized communities. In Australia between 2001 and 2012, more than half of all prosecutions under HIV/AIDS legislation involving heterosexual sex were defendants with an African heritage. Similarly, in a study based in California between 1988 and 2014, Black or Latinx made up two-thirds of the people who came into contact with the criminal justice system based on their HIV status, although they make up only one half of the population living with HIV/AIDS in that State. Over half of the people criminalized are extremely young, that is, under the age of 21 years. In Canada, the disproportionate impact of the legislation on Black communities is also noteworthy. Of the people who faced criminal charges related to HIV non-disclosure since 1989, 23 per cent were Black and 18 per cent were immigrants. 42 per cent of women charged were indigenous.

Furthermore, the criminal law related to HIV/AIDS no longer make sense given pre-exposure prophylaxis (PrEP) and anti-retroviral therapies (treatment-as-prevention or TasP). PrEP is taken by those at risk of *being* infected: it is a protective measure that reduces the risk of contracting HIV among sero-negative people. In 2017, the FDA approved Truvada, which prevents HIV cells from duplicating. Taken every day, it can reduce risk to up to 99 per cent. In contrast, anti-retroviral medication are taken for those with HIV infection. The pills suppress viral loads, so they are ‘negligible’ or ‘effectively zero’ and therefore the virus is not transmittable. Given the existence of pre-exposure prophylaxis and anti-retroviral therapies, criminalizing non-disclosure is highly discriminatory. This is because people on low incomes or without health insurance have little incentive to reveal their HIV status and therefore gain access to anti-retrovirals. They also struggle to access such medical technologies, which also makes them at a significantly higher risk of being criminalized. In other words, poorer and marginalized people living with HIV/AIDS are less likely to have access to the biomedical innovations that severely reduce the risk of transmitting the virus and being infected by it; they will be disproportionately criminalized. As happened with the criminalization of COVID-19, criminalising HIV/AIDS is most harmful to people who are most vulnerable.

Criminalization has worked alongside another shift in the state management of HIV/AIDS in Europe. Although there are country-wide differences, a significant turning point was the financial crisis of 2008. Up to that time, European states had operated according to a rights-based model founded on the European Convention on Human Rights and the European Social Charter, both of which asserted a universal right to health. In the UK, positive initiatives included the syringe exchange programme (introduced in 1987), food aid programmes, and psychological support groups. In the U.S., a successful example of the ‘universal rights’ approach was the passing of the Americans with Disabilities Act of 1990, which gave people living with HIV/AIDS protections in employment and healthcare, as well as cementing their right not be discriminated against. The law aimed to ensure that people with disabilities have the same rights and opportunities as everyone else – and those ‘people’ including those living with HIV/AIDS.

After 2008, however, the emphasis on universal rights changed towards ‘risk management’. ‘Efficiency regimes’, ideas about ‘containment’, and protecting the intellectual property rights of pharmaceutical companies came to the fore. As universal or broadly-based rights fell out of favour, neoliberal policies emphasized the need to prioritize certain populations, including ensuring that risk was not spread to previously unaffected groups and assessing policies to ensure that they were economically efficient. In Britain after 2008, there were sweeping cuts to health and social budgets, including incapacity benefits and psychosocial services, all of which proved particularly harmful to people living with HIV/AIDS.

There was also a distinct change in *tone* amongst researchers. The early years of HIV/AIDS management emphasized individual and community needs; the voices of those people affected were considered paramount in understanding and treating the disease. Under this new dispensation, however, the abstract concept of ‘populations’ who were ‘at risk’ dominated, in addition to the financial implications of responses to the disease. An example can be found in a 2010 article published in *AIDS* and subtitled ‘A Cost-Effective Approach for Treating and Preventing HIV’. The article set out to provide an ‘economic evaluation of the

increment net benefit' associated with expanding the provision of HAART (Highly Active Anti-Retroviral Therapy). Using a 'mathematical model' and a 'microsimulation model describing the clinical and economic course of AIDS', it assumed a 'willingness-to-pay threshold of US\$50,000 per quality-adjusted life year'. Its main themes include 'limiting economic burden' and 'cost effective strategies'. The author's proposed scheme was predicted to offer a 'net benefit of US\$900 million'. Nothing could have been further from the community-based organizing of individual activists and gay community groups, who insisted on the need to unite in solidarity with other minoritized and discriminated against groups in order to demand the right of everyone to be treated with dignity and respect.

Throughout the period, people most affected by HIV/AIDS resisted stigmatization and discrimination. They quickly mobilized, keen to understand the disease, prevent transmission, and educate the wider public. The most famous of the activist groups was ACT UP (AIDS Coalition to Unleash Power), a grassroots democratic political movement. Founded in 1987, it borrowed campaigning tactics from civil rights organizations, feminist health movements, and antimilitarism groups. ACT UP was extremely diverse in terms of personnel, strategies, and tactics. Their chief aim was to disrupt 'business as usual' through sit-ins, die-ins (for example, in front of the White House or in Wall Street), street theatre, the hanging of political effigies (for example, the vampiric effigy of California Representative William Dannemeyer who attempted to introduce a Bill requiring doctors to report to the authorities the names of anyone who tested positive for HIV), poster campaigns, public acts of mourning, community-based art works, and public displays of grief over the death of members of their communities. They also criticized the pharmaceutical industry who allowed profits from essential drugs such as Daraprim (which helps prevent pneumonia in people with HIV/AIDS) to skyrocket 50-fold from \$13.50 to \$750 per unit in 2015. They proved effective communicators, especially when reading out the names of 1,920 people who had died of AIDS and whose names were sewn into AIDS Memorial Quilt. Sponsored by The Names Project Foundation in San Francisco, the quilt covered the grounds of the Capital equivalent to two football fields. Mourning the dead was an important part of their activism. While many families erased or ignored the dead ones' lovers, queer obituaries broadcast the truth. They were also angry: queer mourners even scattered the ashes of their loved ones on the White House lawn. They made death political.

Notable victories of AIDS activism include streamlining the U.S. Food and Drug Administration's (FDA's) processes for approving drugs such as AZT and other anti-retrovirals, advocating for clean needle exchange, insisting that HIV-positive women be included in drug trials, providing accurate information to the public, and working to create adequate social services and disability pensions. ACT UP also championed the right to sexual pleasure and bodily self-determination. They linked up with WHAM (Women's Health Action and Mobilization), uniting debates about AIDS and abortion. Instead of remaining as objects of medical and scientific enquiry, members of activist communities directly challenged the medicalizing discourses. In 1985, after a test became available for the HIV virus, they argued persuasively against mandatory testing, on the grounds of privacy, fears that mandatory testing would be used to discriminate against people living with HIV/AIDS, and that it risked divided sick people into the 'guilty' and the 'innocent'. Instead, they advocated for voluntary, anonymous testing combined with self-regulation and education in safe sex practices.

Lesbians were very active in the movement. Because they, too, were under attack by conservative media and politicians, they understood the struggles of their gay brothers. Lesbian activists were particularly prominent in organizing blood drives, volunteering as 'buddies', marching in protest movements, and staging public prevention events. Prominent activists include Black lesbian feminists such as Evelyynn Hammonds (who had been involved with the Combahee River Collective), Linda Villarosa (who, in 1987, co-wrote the first article on AIDS in the ethnic magazine, *Essence*), Cathy Cohen (author in 1999 of *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics*), and the Black lesbian and gay organization BAM! (Black AIDS Mobilization).

Art played significant roles in the resistance strategies of all activist groups. 'Gran Fury' was the artistic wing of ACT UP. One of their billboards (exhibited in Soho and Harlem as part of an exhibition by Whitney Museum) was entitled 'Welcome to America'. The text read: 'Welcome to America: the only industrialized country besides South Africa without national health care'. The power in the billboard rested in the fact that it was not only addressing problems associated with HIV/AIDS but also related issues of homelessness, reproductive rights, poverty, and inequalities.

ACT UP was vocal in resisting the artistic commercialization of AIDS, staging their own counter-artistic

campaign. The most prominent example of this was their response to the November 1992 appropriation of Therese Frare's photograph of David Kirby dying in his father's arms by the fashion-sweater company Benetton. Even though Kirby's family approved the use of the photograph on the grounds that it would draw attention to their son and the AIDS epidemic, ACT UP protested. They published a version of the advertisement with the statement 'There's only one pullover this photograph should be used to sell', with a picture of a condom and their logo 'SILENCE = DEATH'. [See <https://collections.vam.ac.uk/item/O90886/theres-only-one-pullover-this-poster-dibb-andrew/>]

Another powerful (although also controversial) artistic responses was 'Let the Record Show', which appeared at the New Museum of Contemporary Art in lower Manhattan from November 1987. Created by 'Gran Fury', these artists sought not to elicit empathy but, rather, anger – fury, in fact. 'Let the Record Show' was a photo-installation. The main panel showed the Nuremberg Trials for 'crimes against humanity' with six people added to the frame: these were Jerry Falwell (televangelist who claimed that AIDS was 'God's judgment'), William Buckley (columnist who argued that people with AIDS should be tattooed on their upper forearm), U.S. Senator Hesse Helms (who recommended quarantining of those who were HIV-positive), Cory SerVass (President of the AIDS Commission who contended that it was 'patriotic to have an AIDS test'), an anonymous surgeon (who admitted to being pleased to now having a good reason for hating 'faggots'), and President Ronald Regan (who refused to even say the word 'AIDS' during the first six years of the epidemic). Above this photomontage was a pink triangle, notoriously imposed on homosexuals during the Nazi persecution and signalling the genocidal outcomes of governmental responses to AIDS. ACT UP's 'SILENCE = DEATH' logo appeared in neon lights, referring partly to the silence of those who were living with AIDS yet not willing to step up publicly as activists. But, more important, 'SILENCE = DEATH' referred to systemic silences – the failures of state and scientific authorities to seriously tackle the crisis. Below the neon sign was a running text providing statistics and further evidence of the travesty that was taking place 'in full view'. 'Let the Record Show' channelled the gay communities' fury. As sociologist Deborah B. Gould reminds us,

“feeling and emotion are fundamental to political life, not in the sense that they overtake reason and interfere with deliberative processes, as they are sometimes disparagingly construed to do, but in the sense that there is an affective dimension to the processes and practices that make up ‘the political’, broadly defined.”

In the case of 'Let the Record Show', the indictment had shifted from 'irresponsible' and 'promiscuous' HIV/AIDS sufferers to the real cause of the epidemic: systemic governmental, scientific, medical, and religious failures.

ACT UP was also important in theorizing sex and sexuality. The early activists drew upon the writings of Michel Foucault. According to activist Douglas Crimp, Foucault's *The History of Sexuality* 'had something of the effect that Herbert Marcuse's *Eros and Civilization* had on political movements during the 1960s'. By 1990, however, they had the writings of 'Queer theorists' such as Judith Butler in *Gender Trouble* and Eve Kosofsky Sedgwick in *Epistemology of the Closet*. Such texts changed worlds far beyond LGBTQ+ ones.

Just as there is no such things as 'the' gay community (and even the plural 'gay communities' does not do justice to the full range of differences) so, too there were impassioned disagreements about how people should respond to the crisis. As the epidemic stretched on, fatigue and 'burn-out' set in. Witnessing friend after friend die took a toll. Survivors' guilt arose, alongside feelings of helplessness and a sense of abandonment.

Responses split, most notably between activists who advocated condom use, monogamy, or celibacy, as opposed to those who believed that such approaches were 'anti-sex' or represented internalised homophobia. When gay spokesmen like Larry Kramer contended that gay men should simply stop having sex, others (such as Charles Jurrust) accused him of 'unleashing hysteria within our community'.

In the early years of the epidemic, one of the most furious debates was sparked by Michael Callen and Richard Berkowitz, both 27-year-old gay men who admitted that they had 'been excessively promiscuous' in their sexual lives and were, consequently, 'victims' of AIDS. As a response, they turned against 'promiscuity'. The first sentence of an article entitled 'We Know Who We Are. Two Gay Men Declare War on Promiscuity', and published in *The New York Native* in November 1992, Callen and Berkowitz (along with Richard Dworkin) announced that 'Those of us who have lived a life of excessive promiscuity on the urban gay circuit of

bathhouses, backrooms, balconies, sex clubs, meat racks, and tearooms know who we are'. They admitted that they could 'continue to deny overwhelming evidence that the present health crisis is a direct result of the unprecedented promiscuity that has occurred since Stonewall, but such denial is killing us.... Deep down, we know who we are and we know why we're sick'. Controversially, Callen and Berkowitz adhered to 'Overload Theory' in which 'we have overloaded our immune systems with *common* viruses and other sexually transmitted infections. Our lifestyle has created the present epidemic of AIDS among gay men'. In other words, 'promiscuity' (not a *virus*) was weakening gay men's immune systems. They appealed to fellow gays to repudiate 'urban gay male promiscuity' in order to save lives. They concluded their article with a call for change, stating:

"As individuals, we must care enough about ourselves to begin this re-evaluation: gay men are dying. As a community, we must initiate and control this process ourselves.... The motto of promiscuous gay men has been 'So many men, so little time'. In the '70s we worried about so many men; in the '80s we will have to worry about so little time."

The gay community was divided in their attitude to Callen and Berkowitz's call-to-arms so, the following year, they followed up their *New York Native* article with a pamphlet entitled *How To Have Sex in an Epidemic* (1983). The pamphlet, which is widely recognised as the first 'safe sex' manual for the gay community, sold out within days. Callen and Berkowitz reiterated their claim that 'our lifestyle has created the present epidemic of AIDS'. However, their solution was not an end to promiscuity but the mobilization of the gay community to provide advice for keeping healthy. They insisted that

"Men loving men was the basis of gay male liberation, but we now have created 'cultural institutions' in which love or even affection can be totally avoided. If you love the person you are fucking with – even for one night – you will not want to make them sick."

In other words, it was important to include love and ethical behaviour into gay liberation. Crucially, this had to be driven by the gay community itself, and not outside authorities: 'as a community we must initiate and control this process ourselves'.

The lack of agreement over sexual practices paled beside conflicts over strategy and identity. This story has been told eloquently by other historians but, in shorthand, it was a tension between white gay male activists on one side and people of colour and women on the other. One side was accused of defending white privilege and conformism; the other side, of political utopianism. ACT UP had operated an 'Inside/Outside' strategy : in other words, while some parts of the movement worked 'in direct, personal relationship to government or corporate officials... having intimate interactions, and creating identification', other parts of the movement 'provided backup and pressure through street actions... playing the role of Outside'. As Sarah Schulman explains, the problem was that 'most people in power were white males.... And this determined which AIDS activists had the potential to be Inside and which ones would be relegated to Outside'. Men and women of colour were minoritized even within the movement, as were lesbians.

Accusations of racism rose to the fore. Because the leadership of ACT UP was white, educated, and well-off, many Black activists felt marginalised either because they lacked the economic and personal support mechanisms to devote their energies and time to The Cause, or because they were deliberately being relegated to the margins of the movement. In the words of Alexandra Judasz in 'Forgetting ACT UP', 'when ACT UP is remembered ... other places, people, and forms of AIDS activism are disremembered'.

The 'Minority Action Committee' (MAC) of ACT UP drew attention to racism within the organization. Led by gay men of colour, MAC enlisted the support of SisterLove, the Black Church, the Nation of Islam, and other organizations for people of colour in order to argue that finding a 'magic bullet' (that is, prioritizing 'drugs into bodies') was less important strategically than transforming cultures of discrimination and inequality. They were upset with the assumption that people of colour were drug users. They were furious by ACT UP's failure to consult Black and Latinx communities. When the white male advocates in the 'Treatment and Data Committee' of ACT UP accused the street activists of setting the movement back by alienating allies in science and government, they responded with bitter claims that ACT UP sought respectability and assimilation over political transformation. Of course, it is important not to forget (or 'disremember', in Judasz's words) that there had been important anti-racist activism within the movement. In an article entitled 'ACT UP, Racism, and the Question of How to Use History', Deborah B. Gould reminds us that ACT UP had forced the

CDC to

“expand its definition of AIDS to include the infections that were killing women and poor people with HIV, a disproportionate number of whom were black and Latino/a. They successfully fought the exclusion of women from experimental drug trials. They fought for needle exchange programs, housing for PWAs, and medical treatment for prisoners with AIDS. They demonstrated for equal access to health care, placing the fight for national health insurance at the center of the fight against AIDS.”

In other words, it is important not to forget that it was members of ACT UP who exposed racism within their own organization and took on ‘crucial battles’ alongside People With AIDS who were Black, poor, and otherwise minoritized. But it wasn’t enough.

The introduction of medications also changed the dynamic of the movement. The (erroneously called) ‘post-AIDS’ world, saw a depoliticization, individualization, and commercialization of HIV/AIDS. Power moved away from local communities and support groups and towards state regulation and medical as well as pharmaceutical interventions. When ‘gay lifestyles’ became more assimilationist, local authorities shifted their attention to drug users. In an especially astringent assessment in 2017, critical sexuality studies scholar Gary Dowsett maintained that gay men were ‘all pill-up and potion-ed into subjection in the biomedical re-regulation of our sexuality’. The gay lifestyle now included adding ‘ART to our shopping list of goods and services... along with moisturiser, protein powder and dildos’. Gay men

“behave as good citizens, marrying our own kind, constituting our diverse minority, raising our rainbow young, managing our health and wellbeing, consuming our increasing list of necessities, with a greater proportion of our disposable income directed towards sexual paraphernalia, and paying for every last skerrick [sic] of it.... We are no longer gay; we are men who consume sex with men. The term ‘MSM’ finally makes sense as a market niche.”

Queer theorist Jasbir K. Puar has coined a witty term for this move to respectability: it is ‘homonormativity’. And it replicates some of the same hierarchical ideals found in *heteronormativity* in terms of race, class, gender, and nation-state.

In conclusion. HIV/AIDS remains a global problem. In 2019, 38 million people were living with HIV. It is yet another example of health as a political as much as a medical issue. But there is no single story of HIV/AIDS. This is why I want to end with Tom Moran, the photographed man with whom I started this talk (see <https://www.icaboston.org/art/nicholas-nixon/tom-moran-quincy-massachusetts-july-1987-series-people-aids>). Although I agree with the criticism of Nixon who took the photographs, it is important to note that Tom Moran wanted the photographs to be taken. In his words,

“A photograph lasts a long time after you’re gone.... There’s a part of me that’s afraid that people will forget me.... I thought it might be good to be in this project, where part of me might possibly be here when I’m not here.”

And Tom Moran was much more than his photograph: he was secretive, abrasive, loved by his family, a good friend, a man with a cheeky smile. In 1996, Thom Gunn composed a poem in the ‘Circle of Peace’ at The National AIDS Memorial Grove in San Francisco’s Golden Gate Park, the only federally designated AIDS memorial in the U.S. Some lines go like this:

*Walker within this circle,
pause.
Although they all died of one cause.
Remember how their lives were dense
With fine, compacted difference.*

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