

Uploading HIV/AIDS. Digital Platforms, Gender Justice, and New Legal Challenges Between the US and the EU

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ABSTRACT

Starting from the HIV historical reconstruction and its first regulations between the US and the EU, the article examines how the law changes when digital technologies come into play. Indeed, since the beginning, HIV/AIDS activism has been strictly related to the emerging cyberspace, entangling their roads as never happened before. Then, focusing on the role played by HIV Prevention and its digitalization, new legal issues emerged. However, social stigma and outdated laws still prevent effective legal responses, leaving people HIV-positive and HIV-negative who take preventive biomedical devices without adequate protection.

Muovendo da una ricostruzione storica dell'HIV e delle sue prime regolamentazioni negli Stati Uniti e nell'Unione Europea, l'articolo analizza le complessità introdotte dalla digitalizzazione, interrogandosi su come le tecnologie digitali riconfigurino le categorie normative e i dispositivi di tutela. Fin dalle origini, l'attivismo HIV/AIDS si è intrecciato in modo strutturale con lo sviluppo del cyberspazio, dando luogo a nuove forme di soggettivazione politica e di mobilitazione collettiva. In seguito, focalizzandosi sulle varie forme di digitalizzazione della prevenzione – in particolare dei dispositivi biomedici come la PrEP – il contributo mette in luce l'emergere di nuove criticità giuridiche, tra cui la gestione dei dati sensibili e la sicurezza digitale. In questo quadro, la persistenza di norme obsolete e lo stigma intersezionale continuano a ostacolare risposte giuridiche efficaci, esponendo a rischi strutturali tanto le persone sieropositive quanto quelle negative ma che accedono a strumenti di prevenzione.

KEYWORDS

HIVregulation, intersectionalstigma, digitalactivism, digitalplatforms, privacy and security

regolamentazione dell'HIV, stigma intersezionale, attivismo digitale, piattaforme digitali, privacy e sicurezza digitale

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Introduction

Drawing on the framework of intersectionality¹ and assuming a comparative perspective between the United States (US) and the European Union (EU), the article explores the role of cyberspace in the evolution of HIV regulations, questioning what new legal complexities and ongoing challenges digitalization has introduced in both contexts. Intersectionality related to HIV helps not only to analyze how legal and social responses to the virus disproportionately affect individuals at the intersection of multiple marginalized identities, but also how HIV-related legal frameworks are shaped by serophobia (HIV-related stigma)² and by broader heteronormative and essentialist biases and social norms present in legal and societal structures, which influenced HIV criminalization, neoliberal governance and the current digital issues.

The article focuses on the comparison between the US and the EU due to their distinct and leading legal traditions and approaches to HIV and the new common challenges that both contexts are facing. The US has historically relied on a criminalization-based response to HIV transmission, exposure, and disclosure, often reinforcing specific punitive measures against people living with HIV/AIDS (PLWHA) and the at-risk population. Meanwhile, despite generally integrating public health and human rights perspectives into its fragmented legal framework, the EU has also provided a criminalized approach. Both legal frameworks – whether through HIV-specific laws or general criminal provisions – construct offenses into three main categories. The first includes transmission-related offenses, where the act of transmitting HIV is criminalized either through explicit HIV-specific laws or under general assault provisions treating transmission as bodily harm. The second category covers

¹ Intersectionality refers to how various forms of social stratification – such as race, gender, and class – intersect to create overlapping and interdependent systems of discrimination. It emphasized the need to consider the complexity of lived experiences and the multiple dimensions of identity in analyzing power structures and social and gender justice issues. CRENSHAW 1989.

² Goffman's concept of stigma refers to the social process by which individuals are devalued based on perceived differences, leading to discrimination. This dynamic creates a divide between the "normal" and the "stigmatized", resulting in internalized shame and social isolation for those affected. GOFFMAN 2022.

endangerment offenses, which penalize actions that create a risk of HIV transmission, even when no actual transmission occurs. The third category consists of non-compliance offenses, which criminalize failures to disclose HIV status or to take legally defined precautionary measures. In particular, this third category – disclosure – results at the center of renewed debates due to the challenges brought by digitalization and HIV prevention. These approaches have faced criticism for perpetuating stigma, discouraging transparency with healthcare providers, and undermining shared responsibility for sexual health and public health³. Comparing these models provides insight into how legal systems interact with the digital transformation of HIV-related policies, revealing how digitalization has reshaped not only access to prevention and treatment, but also the broader legal narratives surrounding HIV and the shared and diverging challenges in the regulation of the virus in the digital age.

The article is divided into three parts. Initially, it investigates the first phase of HIV, its regulatory responses, and the rise of a particular form of activism in a new environment, cyberspace, and a new era, the Neoliberal Era. Indeed, the neoliberal management of HIV, prioritizing profit over public health, shifted responsibility from the state to individuals, reinforcing simultaneously traditional narratives – heteronormativity, essentialism, and monogamy – on relationships and within and through regulations⁴. Secondly, the article explores the alterations resulting from the entanglement of new biomedical prevention devices and digital tools, which drastically shift HIV social construction and drive fundamental changes and challenges in its regulations. Finally, it highlights the new legal issues that have emerged due to HIV digitalization, and the clashes with outdated regulations and legal biases.

By adopting an intersectional approach, this article highlights how structural inequalities are evolving in the digital era, relocating HIV regulation as a crucial issue of social and gender justice.

1. 1980s-2000s: HIV/AIDS governmentality

The HIV/AIDS appearance led public authorities to set measures which, following and shaped by scientific discoveries, were contested for undermining multiple rights. However, the interplay between the medical understanding of the virus, the political and legal responses, and the social construction of the individuals – in Foucauldian words, the virus governmentality⁵ – sparked new forms of resistance characterized by the rise and use of cyberspace. Indeed, since HIV/AIDS knowledge construction was deeply related to power structures, it was inevitably also entangled with social resistance⁶. Therefore, since its beginning, the virus construction and government have involved multiple intersectional forms of surveillance, discipline, punishment, subjectivation, knowledge, market interests, but also *parrhesia*⁷.

³ For a broader view of the HIV regulatory frameworks and discussions see SULLIVAN, FIELD 1988; ROSE 2001; LAZZARINI et al. 2002; BURRIS et al. 2007; MCARTHUR 2007; WEAIT 2007, 2011; KLEIN 2009; DODDS et al. 2009; ROBINSON 2010; KAPLAN 2012; STEFFEN 2012; NEWMAN 2013; PERONE 2013; MCCALLUM 2014; BURDA 2015, 2016; FROST 2016; SMITH 2016; WHITE 2016; BONE 2017; PAYNE 2018; PERRONE 2020; DORFMAN 2024.

⁴ COOPER 2008; 2017.

⁵ Foucauldian *governmentality* refers to how (bio)control over the population is exercised through various forms of governance – political, social, medical, and economic – subjectivizing individuals through mechanisms of self-regulation aligned with public objectives. FOUCAULT 2007, 2008.

⁶ For a broader theorization of resistance and sexuality's power structures, see FOUCAULT 1978.

⁷ Foucauldian *parrhesia* – “fearless speech” – represents openly and ethically speaking truth, even when facing personal risk. Rooted in ancient Greek philosophy, *Parrhesia* involves both the speaker's courage and moral duty and the listener's responsibility to engage with uncomfortable truths, serving as a form of resistance to established oppressive power dynamics. FOUCAULT 2011.

1.1 From Gay-related immune deficiency (GRID) to acquired immunodeficiency syndrome (AIDS), to the Human Immunodeficiency virus (HIV)

In the early 1980s, both in the US and Europe several cases of Kaposi's sarcoma and *Pneumocystis carinii* pneumonia (PCP) – a rare cancer and serious infection respectively – were reported and associated with unexplained immunodeficiency among young gay men⁸. Soon, physicians from both regions found the disease's sexual transmissibility and the sexual orientation of the subjects. Due to this last characteristic, the new infection was first called gay-related immune deficiency (GRID), strengthening a yet affirmed stigma. As a result of the initial “gay lifestyle” framing, women's experiences with HIV were marginalized or ignored⁹. However, when the same symptoms of the disease were further found in subjects not related to gay or bisexual sexual orientation – people who injected drugs (PWID), pregnant women and newborns, racialized communities, and sex workers – scientists changed the medical definition into acquired immunodeficiency syndrome (AIDS), shifting stigma, which intersected new, even if yet stigmatized, subjectivities¹⁰. From 1983 to 1985, researchers identified the virus responsible for the epidemic, naming it Human Immunodeficiency Virus (HIV), and its zoonotic origins: through the “spillover” – the virus jump – from apes in Cameroon and Congo to humans. This last discovery strengthened the racial dimension of the related stigma¹¹.

Despite the demonstration of not being a gay sexual effort, however, HIV/AIDS remained socially constructed as a consequence of sexual liberation. The social discourses during these two decades were first built on the paradigm of *heterosexuality v. homosexuality*, then shifting to *heteronormative, healthy, and good sex v. promiscuous, risky, bad sex*, in other words, from groups to practices¹². At the time, mainstream media significantly influenced these narratives, reinforcing negative perceptions of desire and sexuality and fueling social anxiety and stigma¹³.

The scientific debate on lifestyle practices during the HIV crisis reflected broader societal divisions, initially polarized between condemning sexual behavior and drug addiction. Early on, questions arose about whether HIV, sexual activity, or drug use caused AIDS. As the “causation debate” evolved, during the epidemic's second decade the focus shifted to treatments, particularly in the context of pharmaceutical competition. This included disputes over screening tests and antiretroviral therapies, especially AZT (Zidovudine), the first approved medication, criticized for its side effects and labeled by some as “AIDS by prescription”. These debates highlighted the growing influence of biotech firms, with the US-based Gilead Sciences emerging as a dominant force in the global development and marketing of HIV treatments¹⁴. This evolution illustrated the HIV/AIDS crisis global dimension, where multinational corporations, international bodies, national political, legal, and medical fields, NGOs, pharmaceutical industries, and social movements were

⁸ Centers for Disease Control and Prevention, 1982. *A Cluster of Kaposi's Sarcoma and Pneumocystis carinii Pneumonia among Homosexual Male Residents of Los Angeles and range Counties, California*, 31(23), 305 ss. Available at: <https://www.cdc.gov/mmwr/preview/mmwrhtml/00001114.htm#:~:text=In%20the%20period%20June%201,Angeles%20and%20Orange%20counties%2C%20California> (accessed 17/9/2024).

⁹ COREA 1992; ELBAZ 2003.

¹⁰ MBALI 2024, in WIESNER-HANKS, KUEFLER (eds.).

¹¹ HIV infection occurs when the virus's RNA is converted into DNA within the host cell by reverse transcriptase, enabling the production of new viruses. The primary cause of the HIV/AIDS pandemic is HIV-1 group M, although earlier cross-species transmissions also occurred. These viral transmissions, a result of historical interactions between species, produced different strains. Subtype C spread in Sub-Saharan Africa, subtype B in the US and Europe, while group O appeared in Cameroon. By the 1960s, group M's superior transmission capacity overtook other variants. See QUAMMEN 2012.

¹² SCHUBERT 2020.

¹³ WATNEY 1997.

¹⁴ For a broader perspective about scientific debate see EPSTEIN S. 1996; and for pharmaceutical and biotech companies' competition see BHIDÈ, DATAR, STEBBINS 2024.

simultaneously involved, revealing the complexity of this new global actors' arena¹⁵.

1.2 HIV regulatory frameworks: criminalizing illness, undermining prevention, surveilling identities

During the first wave of the epidemic (1980s-1990s), the criminalization of HIV occurred both in the US and the EU. Governments responded to the crisis with legal measures that criminalized people living with HIV and AIDS (PLWHA) behaviors on three levels: serostatus disclosure and virus exposure and transmission. Therefore, reflecting the growing public fear and scientific uncertainty, these first regulatory responses framed HIV as not only a medical and moral issue but also a criminal one.

1.2.1 The US

In the US, criminalization took on a particularly aggressive form. In the wake of public hysteria, the Supreme Court's decision in *Bowers v. Hardwick* (1986) upheld the criminalization of consensual homosexual activity. The decision significantly impacted the crisis among LGBTQ+ communities as fear of legal repercussions discouraged people from seeking prevention¹⁶. In 1990, Congress passed the Ryan White CARE Act to provide federal funding for HIV-related efforts. However, to qualify for this funding, states were initially required to implement HIV criminalization¹⁷. Then, various state laws were enacted specifically penalizing PLWHA, often criminalizing serostatus non-disclosure and actions like sexual activity or even spitting and biting, despite saliva being yet demonstrated not to be a viable transmission route¹⁸. The construction of HIV/AIDS inevitably had roots in the so-called "chronological coincidences" entangling with two other US crusades: the criminalization of prostitution¹⁹ and the War on Drugs²⁰.

Most states criminalized any behavior that might expose others to HIV – sexual contact/conduct, needle-sharing, transfer of body fluid, non-disclosure²¹ – framing them under sex offenses, prostitution solicitation, aggravated assault, reckless conduct, wanton endangerment, attempted murder categories, and in public health administrative control measures violations and even in bioterrorism laws²². In contrast, other states did not have HIV-specific laws, but risky behaviors could be prosecuted under general criminal code provisions or general sexually transmitted Infections (STIs) regulations²³. One of the most stringent HIV-specific laws were

¹⁵ MBALI 2024.

¹⁶ *Bowers v. Hardwick*, 478 U.S. 186 (1986).

¹⁷ Ryan White Comprehensive AIDS Resources Emergency Act of 1990, Pub. L. No. 101-381, 104 Stat. 576 (1994), 42 USC S 300ff.

¹⁸ In Alabama, a man was charged with attempted murder and first-degree assault for a bite. The prosecution argued that because he was living with HIV, his bite would be «highly capable of causing death or serious physical injury» and then that it would be considered a “dead weapon” under the law. *Brock v State*, 555 So. 2d, Ala. Crim. App. (1989).

¹⁹ The so-called Mann Act criminalized the sale of sex, White-Slave Traffic Act of 1910, 18 USC §2421 et seq.

²⁰ For a broader perspective, see POZEN 2024.

²¹ LAZZARINI et al. 2013.

²² Arkansas, Colorado, Delaware, Florida, Georgia, Idaho, Illinois, Indiana, Kentucky, Louisiana, Michigan, Mississippi, Missouri, Nebraska, New Jersey, North Carolina, Ohio, Oklahoma, Pennsylvania, South Carolina, South Dakota, Tennessee, Texas, Virginia, and Washington. For a broader view of the wide range of specific laws enacted, see: Ark. Code Ann. § 5-14-123; Col. Rev. Stat. § 18-3-415.5; Fla. Stat. Ann. § 775.0877; Ga. Code Ann. § 16-5-60 (c)-(d); 720 Ilcs. 5/12-5.01; Ind. Code §§ 16-41-14-17, 35-41-2-1, 35-45-16-2, 35-45-21-3, 35-50-2, 35-50-3; Ky. Rev. Stat. §§ 529.090 (3) & (4) and 311.990 (31) (b); La. Rev. Stat. § 14:43.5; Mich. Comp. Laws. Ann. § 333.5210; Miss. Code Ann. § 97-27-14; Mo. Rev. Stat. § 191.677; Neb. Rev. Stat. § 28-934; N.J. Stat. Ann. § 2C:34-5; 10A; N.C. Admin. Code 41A .0202; Ohio Code §§ 2927.13, 2907.25, 2907.241; Okl. Stat. § 1192.1; Pa. Const. Stat. §§ 2703, 2704; S.C. Code Ann. § 44-29-145; S.D. Codified Laws § 22-18-21; Tenn. Code Ann. §§ 39-13-109, 39-13-156; Tex. Penal. Code. Ann. § 22.012 (Texas was the first state to repeal its specific statute in 1994, however, criminalizing HIV under general criminal law provisions); Va. Code § 18.2-67.4;1; Wash. Code § 9A.36.011.

²³ FROST 2016.

those enacted by California, with only Iowa's representing the most draconian. In both states, non-disclosure of HIV status could lead to felony charges even without "specific intent" – despite the general provision requiring it – and even when transmission risk was nonexistent²⁴.

These laws strengthened the HIV-related stigma, "constructing" penis/body fluids as a *deadly weapon* and sexual conduct as *assault* or *attempted murder*. At the same time, most of the states explicitly or implicitly permitted the "condom defense" to demonstrate the absence of the "specific intent" required by most laws, even if neither the intent provision nor the disclosure/prevention defense – when recognized – protected people from prosecutions²⁵.

1.2.2 *The EU*

Different and more differentiated was the European response. Following the US, European countries also enacted HIV-specific laws or prosecuted HIV under general criminal codes, although the less or no enforcement of criminal laws demonstrated since the beginning a more "progressive" tendency. One potential reason for this lack of enforcement could be that European legal responses to the crisis were heavily influenced and shaped by international frameworks, particularly the European Convention on Human Rights²⁶, reflecting a greater emphasis on balancing public health concerns with individuals' fundamental rights. The EU's role in addressing HIV/AIDS rights-based responses was further exemplified by its supranational engagement with local institutions and organizations in Central and Eastern Europe (CEE), addressing the crisis beyond its borders and further contributing to presenting it as a kind of "postmodern actor"²⁷. Nevertheless, countries such as Sweden, Denmark, and Norway introduced specific provisions criminalizing HIV. Sweden criminalized HIV behavior through both existing criminal provisions²⁸ and laws. Under the Communicable Disease Act of 1985, the government required HIV-positive individuals to «provide information about the infection to other people», criminalizing the failure to take precautions even without real transmission²⁹. In addition, with the Infectious Diseases Act of 1988 – which divided infectious diseases into diseases dangerous to society and others – HIV was described as a danger to society. Section 38 of the Act stated the «compulsory isolation of a person who is infected with a disease dangerous to society if the infected person does not voluntarily cooperate» and «if there is good reason to believe that the infected person is not complying with the announced rules of conduct»³⁰. Therefore, HIV criminalization took place from "conduct regulation". Similarly, Section 155 of the Norwegian Penal Code of 1902, applying to a set of «generally contagious diseases» and differentiating penalties between «willfully or negligently» transmission, was implemented to cover HIV³¹. In 1994, the Danish Supreme Court acquitted a man prosecuted for non-disclosure, ruling that the current Section 252 of the Criminal Code of 1930 – penalizing «whoever (...) causes imminent danger to someone's life or mobility» – failed to provide the basis to criminalize HIV non-disclosure³². Therefore, subsection 2 regarding the «life-threatening and

²⁴ Cal. Code §§ 1001.10-1001.11, 1202.1, and § 1202.6 for mandatory testing, 1170, § 647f and 1463; Cal. Health & Safety Code §§ 121070 and 121025 for disclosure, 121055 for compulsory tests, and 120290-120292 for exposure and transmission as a felony prosecution; Iowa Code §§ 709D.2 and 709D.3.

²⁵ WHITE 2016.

²⁶ Council of Europe. 1950. "Convention for the Protection of Human Rights and Fundamental Freedoms". *Council of Europe Treaty Series* 005. Strasbourg: Council of Europe.

²⁷ BOISVERT 2007.

²⁸ Sweden Penal Code of 1960, Chapter 3 §§ 5-6;8-9; Chapter 23 § 1, *Brottsbalk* (1962:700).

²⁹ The Communicable Disease Act of 1985, *Smittskyddslag* (2004:168).

³⁰ The Infectious Disease Act of 1988, *Smittskyddslag* (1988:1472), § 38.

³¹ Norwegian Penal Code of 1902, *Almindelig borgerlig Straffelov* strl.1902, § 155.

³² Højesterets dom, UfR 1994.520/2, April 14, 1994.

incurable disease» was added in response³³. Norwegian and Danish sections and Sweden's approach, applying specifically to HIV, have represented the European "HIV laws" models³⁴.

On the contrary, HIV-specific laws were not introduced in other countries – such as the Netherlands, Finland, Iceland, France, the UK, Austria, Germany, Spain, and Portugal. The criminalization, however, occurred under existing criminal provisions (assault, sexual assault, reckless endangerment, or bodily harm, injury, illness)³⁵. Finally, as for the US, also the criminalization of sex work in most European countries contributed to substantial obstacles in accessing HIV services³⁶.

Although emphasizing harm reduction and even if prosecutions remain rare compared to the US, also in Europe criminal frameworks were enforced. In fact, without practically considering the "specific intent" and the actual transmission and with difficulty related to demonstrating both previous disclosure and prevention, these laws took away from PLWHA the real possibility to defend themselves, shaping social responses.

1.3 HIV/AIDS activism: from Streets and Medical Laboratories to the Digital Avenues

Intersecting identity politics with community-based approaches, HIV/AIDS activism emerged, fighting against regulatory responses and alongside marginalized groups like LGBTQ+ communities, certain populations – such as women – and sex workers. Due to the peculiar PLWHA status of "patient", "research subject", and "consumer", activist organizations criticized political, medical, and legal measures and the business framework around tests and treatments. Among the first and most significant contributors to HIV/AIDS activism worldwide, ACT-UP in the US played a crucial role in redirecting research development, treatment approval, cultural initiatives, and civil disobedience, rehumanizing those affected by the virus who had socially become *the virus*³⁷. The ACT-UP model was quickly reproduced in Canada, Australia, and Europe³⁸. In particular, women-centered groups parallelly emerged from the local – such as ACT-UP's Women's Caucus³⁹ – to the global – with the International Community of Women Living with HIV (ICW)⁴⁰. By fighting stigma, which in their case entangled racist and homophobic perspectives with moral role judgment – *good women v. bad women* and *good motherhood v. evil motherhood* –, women reframed HIV/AIDS also as a feminist issue, driven by intersectional stigma⁴¹.

Similarly, in Europe, organizations like the Terrence Higgins Trust (THT) in Britain, AIDES in France, and Deutsche AIDS-Hilfe (DAH) in Germany provided vital transnational services, including educational campaigns, counseling, care, and research funding. Another form of activism involved jurisdiction-focused organizations, such as the US Centre for HIV Law & Policy in the US and the UK's National AIDS Trust. These movements began collaborating closely with national, supranational, and intergovernmental organizations – World Health Organization (WHO) and the United Nations (UN) – which led to the establishment of the Joint United Nations Programme on HIV/AIDS (UNAIDS), promoting

³³ Act No. 431 of June 1, 1994, Denmark Criminal Code, *Borgerlig Straffelov*, Chapter 25, § 252; 2.

³⁴ HIV-Nordic, HIV and the Criminal Codes in the Northern Countries, Available at: <http://www.hiv-norden.org/Documents/crime%20brochure.pdf> (accessed 18/09/2024).

³⁵ European HIV Legal Forum, HIV Criminalization in the EU. A comparative 20-country report, April 2023. Available at: <https://www.nat.org.uk/sites/default/files/publications/HIV%20criminalisation%20in%20the%20EU.pdf> (accessed 18/9/2024).

³⁶ PLATT 2018.

³⁷ ALTMAN 1994; STURKEN 1997; MBALI 2024.

³⁸ GAMSON 1989.; GOULD 2009.

³⁹ ROTH 1998.

⁴⁰ Available at: <https://www.wlhiv.org/about-us> (accessed 18/09/2024).

⁴¹ BERGER 2004.

a multi-sectoral approach to enhance prevention, treatment, and combat stigma while politically and legally acting as resistance against unjust policies and laws⁴².

The HIV/AIDS movement proved to be both old and new. As a «beneficiary of social movements spillover» – the gay and lesbian movements and the feminist health movement – and by an “expertification” process, activists pressured governments, drug companies, and health agencies, engaging in a critique of medical practices and political and economic strategies, shaping “HIV/AIDS knowledge”⁴³. Its innovation, instead, stemmed from cyberspace’s rise and use, which enabled simultaneous rapid global networking. Activists embraced the Internet as the only free “street and square” for “telling the truth”, such as in the US the online magazine POZ (1994)⁴⁴ and TheBody initiative (1995)⁴⁵, and NAM Publications in the EU (1987) – globally known as AIDSmapi – ones of the firsts digitalizing evidence-based information⁴⁶. In Europe, at the supranational level and on the model of ACT-UP, the European AIDS Treatment Group (EATG) was established, engaging in improving information, increasing research, and empowering people around Europe⁴⁷. Finally, at the global level, the Global Network of People Living with HIV (GNP+), also began using digital tools to advocate for rights and treatment access on a global scale⁴⁸. In a time of widespread misinformation, activists created national, supranational, and global networks, sharing knowledge via websites, forums, newsletters, and online publications, filling gaps left by traditional media. Thus, from the outset, cyberspace became an essential tool and space for organizing local and global responses, challenging stigma, and denouncing unjust regulations⁴⁹.

2. The 2000s: HIV Prevention governmentality

As seen, the first “war against” narrative led to HIV criminalization, the reinforcement of stigma, and the rise of a particular activism. The proven effectiveness of combination antiretroviral therapy (ART) in 1996 marked a pivotal turning point in this dominant narrative and HIV/AIDS historical trajectory, which, however, was better demonstrated only in the second decade of the new Millennium. Thus, a second wave of activism emerged with the rise and delays of HIV prevention biotechnologies implementation. Centering on virus management, the re-new movement expanded its online strategies, reshaping the legal and social landscape but also highlighting new barriers.

2.1 From Post-Exposure Prophylaxis (PEP) to Treatment as Prevention (TasP), to Pre-Exposure Prophylaxis (PrEP)

Significant strides in HIV/AIDS prevention were made yet during the 1990s through the development of Post-Exposure Prophylaxis (PEP), Treatment as Prevention (TasP), and Pre-Exposure Prophylaxis (PrEP), each marking crucial milestones. PEP, which had been available since the 1990s for occupational exposures (healthcare workers) in case of incidents and injuries, expanded its reach in the early 2000s to include non-occupational exposures in cases of sexual contact or needle sharing. Due to the delays and structural barriers, in 2007 the WHO recommended broadening its use⁵⁰.

⁴² PARKER 2011; BROQUA, CALANDRA, in PATERNOTTE, TREMBLAY (eds.) 2015.

⁴³ EPSTEIN 1996; cit. 12.

⁴⁴ See <https://www.poz.com> (accessed 19/9/2024).

⁴⁵ See <https://www.thebody.com/about> (accessed 19/9/2024).

⁴⁶ See <https://www.aidsmap.com/about-us/what-we-do> (accessed 19/9/2024).

⁴⁷ See <https://www.eatg.org/who-we-are/> (accessed 20/9/2024).

⁴⁸ See <https://gnpplus.net> (accessed 20/9/2024).

⁴⁹ GILLET 2003.

⁵⁰ PEP involves taking antiretroviral drugs within 72 hours of exposure and continuing the treatment for 28 days

TasP refers to a public health strategy where HIV-positive individuals take ART to suppress their viral load to an undetectable level. It gained recognition in 2006 and was confirmed by the Swiss Statement in 2008, which stated that “undetectable equals un-infectious”⁵¹. In 2011 was further solidified that effective ART reduced HIV transmission by 96% among serodiscordant couples, transforming TasP into the cornerstone of HIV global prevention, but only theoretically and at the international level⁵². Effectively, the PrEP was the real game-changer. Although approved in combination therapies for HIV-positive individuals in the early 2000s, only in 2010 with the pivotal iPrEx study – among men who have sex with men (MSM) and transgender women – it was accepted that daily PrEP reduced HIV transmission in negative people⁵³. The focus on HIV-negative individuals using PrEP reshaped narratives around sexual responsibility, exposing people to both implicit biases tied to societal judgments and explicit stigma captured by terms like “PrEP whores.” These biases framed PrEP users as simultaneously responsible for their health and promiscuous, mirroring the prejudice of HIV-positive individuals and revealing the enduring moral scrutiny surrounding sexual health⁵⁴. Despite the new scientific developments and health agencies’ guidelines⁵⁵, at the regulatory level, HIV criminalization – even if yet scientifically outdated – remained⁵⁶, shaping activists’ responses and online strategies.

2.2 Uploading HIV Prevention

Alongside stigma and societal misconceptions, the first central and general concern remained how to fit HIV prevention into a history of behavior surveillance, forced status disclosure, and punishment, representing a persistent challenge both in the US and the EU⁵⁷. Thus, the disparities and delays across both contexts precipitated a shift in activism, characterized again by cyberspace to fill the voids.

2.2.1 HIV prevention digital activism: from e-information to #U=U

The first reaction to the TasP unrecognition and lack of PrEP implementation was the spread of info-platforms to globally share up-to-date knowledge, such as PrEPWatch, founded in 2006 in New York by activists and AVAC – a non-profit organization⁵⁸. Similarly, in the UK, Prepster was founded by HIV prevention activists in response to the European delay. However, after more than a decade of political inconsistency and the general unawareness of HIV Prevention, activists launched the U=U global campaign in 2016, highlighting the powerful entanglement between new HIV Prevention activism and new social media (Twitter, Facebook, and Instagram). For the first time, social media sharing allowed the #U=U campaign an unimaginable rapid global dissemination. Particularly, advocacy groups leveraged online communities to share personal stories and called for “public status disclosure”, turning disclosure – historically forced by criminal laws – into an act of resistance. Nevertheless, the

to significantly reduce the likelihood of infection, *Joint WHO/ILO expert consultation for the development of policy and guidelines on occupational and non-occupational HIV post-exposure prophylaxis* 2007, available at: https://iris.who.int/bitstream/handle/10665/43838/9789241596374_eng.pdf?sequence=1 (accessed 30/08/2024).

⁵¹ Swiss Statement 2008, available at: <https://i-base.info/qa/wp-content/uploads/2008/02/Swiss-Commission-statement-May-2008-translation-EN.pdf> (accessed 2/10/2024).

⁵² COHEN et. al. 2011; COHEN et. al. 2016.

⁵³ GRANT et al. 2010.

⁵⁴ SPIELDENNER 2016; GOLUB 2018; CALABRESE 2020.

⁵⁵ See NEWMAN 2013.

⁵⁶ See BURDA 2015, 2016, FROST 2016; WHITE 2016; DORFMAN 2024.

⁵⁷ BALLREICH et al. 2022; COMER, FERNÁNDEZ 2022; DZIUBAN, SEKULER 2021; ROSENGARTEN et al. 2020; YOUNG 2019.

⁵⁸ See <https://www.prepwatch.org> (accessed 2/10/2024).

campaign's fundamental goal was embracing the idea of "treatment as prevention" and finally pushing it into the public space, moving away from the narratives of "care as cure" and the "war against the virus" which has meant the war against individuals⁵⁹.

2.2.2 *PrEP Platformization between Safety and New Harms*

Due to the lack of access to PrEP, specific platforms such as MISTR⁶⁰ – and its "pink version" SISTR⁶¹ – exemplified the rise of tech-driven solutions in the US, enabling users to access PrEP without the need for in-person visits. These platforms, offering online consultations, tests, and delivery, broke down geographic and stigma barriers. From PrEP platformization, the growth of TelePrEP was also supported by the National Alliance of State and Territorial AIDS Directors (NASTAD), providing resources for TelePrEP implementation across states. As a result, within the US, specific states' online programs co-live with MISTR and SISTR services⁶².

In Europe, platforms such as PrEP-Online – started by a group of PrEP users based both in Europe and Asia and working with HIV and LGBTQ+-related organizations worldwide – similarly began to offer virtual services⁶³. Nevertheless, with the rise of online delivery medications, also increased the risks of harmful device marketing increased. Indeed, due to the delay in providing safe PrEP and regulatory barriers, unofficial and potentially unsafe channels spread in certain European countries. Several countries, including Austria, Lithuania, and Bulgaria, reported the prevalent trend of individuals seeking PrEP online, with countries such as Poland and Hungary, which have slower adoption of PrEP due to conservative health policies, reporting high online access through different channels, foreign sources, or buyer's clubs. Additionally, Germany documented some utilization of Telegram groups as delivery services for medication⁶⁴. Confirming a history of engagement in HIV research and market, Prepster – through a research project with the UK THT organization – tested the safety of PrEP generics from online international sellers, publishing the results⁶⁵.

Paradoxically, the implementation of digital clinics such as MISTR or/and specific TelePrEP states' programs was much "easier" in the US, where HIV criminalization pertained to most states and digital data could potentially be used in prosecution, meanwhile Europe, even if acclaimed for its human rights-based first approach, reported an increasing trend of unofficial access. However, in the US although HIV telehealth has expanded access to HIV prevention reducing travel and cost, it also confirmed significant disparities among marginalized groups⁶⁶. Therefore, in both countries, technological evolution highlighted new limits and new dangers increased by structural and systemic barriers.

2.2.3 *HIV Surveillance digitalization*

Just as the "pharmacopower" revealed the duality of drugs as tools of both personal resistance and bodies and identity government, so platforms could act as a double-edged sword, serving as tools of resistance and societal surveillance⁶⁷. Indeed, in the wake of HIV prevention spreading, viral

⁵⁹ See <https://preventionaccess.com> (accessed 2/10/2024).

⁶⁰ See <https://heymistr.com> (accessed 3/10/2024).

⁶¹ See <https://heymistr.com/sistr/?branding=sistr> (accessed 3/10/2024).

⁶² See <https://nastad.org/resources/state-specific-tele-prep-services> (accessed 3/10/2024).

⁶³ See <https://preponline.se/about/> (accessed 3/10/2024).

⁶⁴ AIDS Action Europe, Rapid Assessment on Access to PrEP in EU/EEA Countries, December 2022. Available at: <https://www.aidsactioneurope.org/en/publication/rapid-assessment-access-prep-eueea-countries> (accessed 4/10/2024).

⁶⁵ See <https://prepster.info/buying-prep-online/> (accessed 3/10/2024).

⁶⁶ LABISI et al. 2022.

⁶⁷ General concept of *Pharmacopower* relates to the exerted control over bodies through pharmaceutical

suppression also became a societal expectation, not just a medical objective, wherein PLWHA are judged by their ability to maintain an undetectable viral load. In other words, technological mediation has transformed HIV Prevention into a mix of “public-self virus load monitoring”, performing individual autonomy and self-responsibility in the perfect neoliberal rhetoric of self-government⁶⁸.

An instance could be represented by the app *Every Dose, Every Day* (E2D2), designed to support managing medication schedules, dose tracking, prescription refills, and medical appointments. Developed in 2013 with funding from the CDC’s Division of HIV/AIDS Prevention, the project was led by the Boston-based John Snow Research and Training Institute (JSI) in collaboration with Mad*Pow, a design firm. In the US, it was embedded within larger projects to create a web-based program for clinical providers and community partners about five HIV medications. In terms of privacy, the app claims to adhere to stringent standards, offering password protection to safeguard users’ data from unauthorized access or sharing. Nevertheless, the first problem that emerged was the lack of transparency. Users must agree to the app’s Terms and Conditions (T&C), which offer no alternative but to consent or quit the app. Among the T&C list, there is the acceptance of CDC’s no responsibility for any confidentiality or information sharing with other/third parties and that “certain general data” will be gathered and stored automatically, without explanation about what kinds of data are involved in the definition⁶⁹.

Similarly, European HIV management platforms instances could be *LifePlus* service package – designed by the UK’s THT⁷⁰ – and *4Life4Me* – created by a German Russian activist living with HIV and his team⁷¹. These platforms provided interactive and supporting tools to manage HIV. The development of e-health platforms, however, has introduced similar concerns to those seen in the US for potential vulnerabilities in data privacy about compliance with strict standards of the General Data Protection Regulation (GDPR), which mandates transparent data processing and user consent for sensitive information⁷².

The platforms’ combination of surveillance, self-surveillance, and uncertain data privacy conditions exemplifies broader tensions between the new technological setting and the old legal frameworks, given that such data could ever be weaponized in eventual legal proceedings. Investing in mobile health technologies and digital platforms that can provide easy access to self-testing kits, support services, and follow-up care has been highlighted as an essential step at the national and international level⁷³, but it has also underlined the gaps in data protection and the constant lack of privacy, which characterized the history and stories of PLWHA.

2.2.4 HIV serostatus Disclosure Digitalization

As reconstructed, since the beginning, HIV social construction was rooted in the rhetoric of punishment for the sexual liberation of societies. In the “post-romantic love Era”, where the digitalization of love and sex characterizes societies, these narratives further evolved. Dating apps led to the normalization of what was previously associated with the social stigma of promiscuity, giving space to people with no “mainstream” sexual orientation, however, underscoring new

developments, turning gender, sexuality, and identity into constructs defined by both political and medical systems. PRECIADO 2013; for a specific focus on “PrEP pharmacopower” see DEAN 2015.

⁶⁸ GUTA et al. 2016.

⁶⁹ FRENCH 2019.

⁷⁰ See <https://www.theguardian.com/publicservicesawards/positive-thinking> (accessed 20/10/2024).

⁷¹ See <https://life4me.plus/en/application/> (accessed 20/10/2024).

⁷² EU General Data Protection Regulation (GDPR): Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016.

⁷³ BEECROFT et al. 2024.

challenges due to dominant power structures reproduced from offline to online⁷⁴.

In the contemporary ethical regime of living with HIV or without but taking prevention, online dating apps shifted disclosure from a risk-filled endpoint – face-to-face/violence or rejection – to an initial step in forming relationships, foregrounding HIV status disclosure as a central component of online self-presentation. This is particularly true for Grindr, a dating app – predominantly used by gay, bisexual, trans, and queer people – founded in 2009 and headquartered in California. The platform has ever been considered a relatively safe place for HIV status disclosure, providing a section allowing users to select from several options – HIV positive, positive receiving treatment, negative, or negative using PrEP. In the socio-cultural framework, the «entextualization» of user details underscored how racial and ethnic markers have re-emerged as indicators in selecting “responsible” partners, revealing underlying societal biases. Instead, in the legal framework, since Grindr’s functioning relates to a profile account activation, users disclose their status with other personal data to the provider, leading to potential data privacy violation concerns⁷⁵.

2.3 HIV Prevention Regulatory Shifts

2.3.1 The US

In the US, the 2000s opened with the Trafficking Victims Protection Act of 2000 (TVPA), which, despite being aimed at combating human trafficking, worsened the HIV crisis for sex workers⁷⁶. Additionally, the 2003 Leadership Against HIV/AIDS, Tuberculosis, and Malaria Act, through the anti-prostitution “Loyalty Oath”, further jeopardized sex work conditions, requiring organizations receiving federal funding for HIV as part of the President’s Emergency Plan for AIDS Relief (PEPFAR) to have explicit anti-prostitution policies and positions⁷⁷. In the same year instead, the Supreme Court Decision *Lawrence v. Texas*, struck down sodomy laws, overturning *Bowers*⁷⁸. By decriminalizing same-sex relations, the ruling fostered a more inclusive environment for LGBTQ+ communities seeking access to prevention.

Following trial results on PrEP, the FDA was the first health agency to approve it as part of combination therapy to treat individuals already infected with HIV, but only in 2012 was it approved for HIV prevention and branded by Gilead Sciences as Truvada. The “revolution” coincided with broader healthcare reforms related to the Affordable Care Act (ACA) of 2010⁷⁹. About HIV at that time, the Obama Administration called states to revise criminal laws, since they were scientifically outdated and dangerous for both equality and public health goals⁸⁰. Indeed, PEP, TasP, and PrEP, removing the prevention from the “immediacy” of sex – in other words, disentangling the two acts contrarily to condoms –⁸¹, contributed to increasing the awareness of how criminal laws, their “condom defense”, and the forced disclosure provisions were outdated⁸². However, PrEP access was hampered by multiple forms of discrimination, including criminal laws

⁷⁴ BANDINELLI C. 2022.

⁷⁵ MAZANDERANI 2012.

⁷⁶ The Trafficking Victims Protection Act of 2000 (TVPA), H.R.3244 — 106th Congress (1999-2000), Pub. L. No. 106-386.

⁷⁷ H.R.1298 - United States Leadership Against HIV/AIDS, Tuberculosis, and Malaria Act of 2003, Public Law No. 108-25.

⁷⁸ *Lawrence et al. v Texas*, 539 U.S. 558 (2003).

⁷⁹ Patient Protection and Affordable Care Act, Pub. L. no. 111-148, § 1(b), 124 Stat. 119, 124-25 (2010).

⁸⁰ White House, National HIV/AIDS strategy for the United States, July 13, 2010. Available at: <https://obamawhitehouse.archives.gov/sites/default/files/uploads/NHAS.pdf>.

⁸¹ GROV et al. 2021.

⁸² BONE 2017.

not only directly HIV-related – such as in the case of sex workers –, discrimination of marginalized communities in healthcare and the HIV stigma.

Even if most states remained anchored to their criminal frames, due to the rise of prevention regulatory frameworks began to change. In 2009, a man living with HIV on treatment and with an undetectable viral load was convicted to a 25-year prison for non-disclosure in Iowa after having sexual contact with a man he met online although no transmission occurred. The ruling ignited public outrage and advocacy efforts, marking a significant moment in the reform of HIV criminalization laws⁸³. In 2014, the Iowa Supreme Court, ruling on the case, stated that the state's HIV law could not be applied to prosecute PLWHA for consensual sex that poses no risk of transmission, and Iowa, from the most severe, became the first state to include modern knowledge into HIV statute⁸⁴. In 2016, Colorado, with Senate Bill 146, repealed its laws and narrowed the scope of criminalization, focusing more on intent and actual risk rather than punishing individuals for their HIV status alone, and mandated that insurance carriers cover PrEP and out-of-network services for TelePrEP, ensuring broader access to preventive care⁸⁵. California also significantly reduced penalties with Senate Bill 239, which dismantled most of the state HIV laws and provisions, from mandatory tests to disclosure to differentiating and specifying between misdemeanor and felony⁸⁶. However, California reforms are particularly noteworthy. Indeed, by rewriting the new Health and Safety Code section 120290 (h), the State afforded certain privacy protections: all identifying characteristics of the complaining witness and the defendant must be worded to protect their privacy unless otherwise requested. Until the verdict, lawyers, law enforcement personnel, and court staff are obliged not to discuss the identifying characteristics and release them publicly. Only if the person is found guilty, then those protections no longer apply⁸⁷.

In the meantime, PrEP low use led the CDC in 2017 to recommend PrEP full coverage under the ACA provisions⁸⁸, and later, the Department of Health and Human Services (HHS) endorsed the use of PrEP in the US plan aiming to end HIV by 2030⁸⁹. Then, the FDA expanded Truvada's indication to include adolescents, addressing a significant gap in sexual health for young individuals. Following the PrEP implementation wave, other states also revised their HIV regulations. Michigan, for instance, finally reformed its bioterrorism regulation, focusing on actual harm and intent to transmit⁹⁰.

Nevertheless, half of US states still criminalized HIV/AIDS with crystal clear outdated laws –both culturally and scientifically – requiring to federally address the issue.

2.3.2 The EU

As previously reconstructed, despite European countries having historically been at the forefront of rights-based approaches, HIV/AIDS criminalization occurred. In the early 2000s, for instance, the Danish Criminal Code was further amended, adding subsection 3 to Section

⁸³ COX 2016.

⁸⁴ *Rhoades v State*, 848 N.W.2d 22, 26 (Iowa 2014).

⁸⁵ Colorado SB 146, 2016.

⁸⁶ Cal. SB 239, 2017. The bill repealed or/and amended multiple sections of both Health and Safety Code (HSC) and the Penal Code (PC), i.e. HSC §1621.5; HSC §1603.1(a); HSC §1603.3(b); HSC §120290; HSC §120291, §120292; PC sections 1001.10 and 1001.11; PC §1202.6; PC §1463.23.

⁸⁷ See HSC §120290 (h) (2); (3); (4) as amended by Cal. SB 239, 2017.

⁸⁸ US. Pub. Health Serv., Preexposure Prophylaxis for the Prevention of Hiv Infection in the United States – 2017 Update 11 (2017), Available at: <https://www.cdc.gov/hiv/pdf/risk/prep/cdc-hiv-prep-guidelines-2017.pdf>.

⁸⁹ HHS *Ending the HIV Epidemic in the U.S.(EHE)*, 2019. Available at: <https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/overview>. (accessed 2/10/2024).

⁹⁰ Michigan HB 6016, 6020, 6022, and 6030 amended various sections of the Public Health Code (2019), updating terminology and HIV reporting and testing requirements.

252. The new provision stated that the Minister of Justice, «after a consultation with the Minister of Health»⁹¹, resolved which diseases are covered by the law. By Executive Order No. 547 in the same year, among life-threatening and incurable diseases, it was explicitly determined that HIV/AIDS was covered by section 252(2)⁹². Similarly, in a 2004 decision, the Swedish Supreme Court confirmed that engaging in sexual intercourse without a condom constituted unacceptable risk-taking for individuals infected with HIV, even if under antiviral treatment⁹³.

Contrarily to the US, however, HIV “decriminalization”, even if gradually, began earlier. Indeed, in those years, the European human rights approach remained visible, especially looking at the emerging role of the European Court of Human Rights (ECtHR), which underlined the necessity of balancing public health measures with individual rights in *Enhorn v. Sweden* in 2005. The case involved a man who was forcibly isolated by Swedish authorities for almost a year to prevent the spread of HIV despite posing minimal transmission risk. The ECtHR addressed the legality of compulsory isolation measures in public health cases under the European Convention on Human Rights, finding Sweden in violation of Article 5 (right to liberty and security). The Court found that while containing infectious diseases can justify certain restrictions, they must be «strictly necessary» and proportionate to the risk posed by the individual and should only be employed when «less severe measures have been considered and found insufficient»⁹⁴.

Although the decision, in the same year, in a broader reform of the Norwegian Penal Code, HIV still fell under Section 237 of the new Code, which, despite focusing more on actual rather than potential risk, reconfirmed the role of «particularly reckless behavior» in transmission, continuing to criminalize sexual conduct⁹⁵.

Nevertheless, after the first decade of the 2000s, something began to change in both national legislative and judiciary frames. From the Working Group on Transmission of HIV/AIDS recommendation, Denmark was the first European country to finally suspend the application of Section 252.2 for HIV in 2011⁹⁶. Similarly, in 2013, the Swedish Skåne and Blekinge Court of Appeal acquitted a defendant previously convicted by the district court of endangering another person, trying to align with updated scientific knowledge and citing the Swiss Statement⁹⁷. However, the Public Prosecutor challenged the acquittal, leading the case to the Supreme Court, which, contrary to the supranational addressing of 2005 and referring to its 2004 precedent, ultimately granted leave to appeal and convicted the defendant⁹⁸. In contrast to the general Swedish strict approach, the legal framework in England and Wales took a more nuanced approach. As clarified in *R v. Konzani* in the same year, for reckless transmission⁹⁹, the complainant had to actively consent to the risk of HIV transmission, requiring prior knowledge of the defendant’s HIV status¹⁰⁰. While disclosure of HIV status was not a legal obligation, it remained crucial for establishing a defense based on informed consent. Notably, the courts also clarified that non-disclosure did not negate consent to sex or constitute rape, further highlighting a focus on intent and informed agreement in determining criminal liability¹⁰¹.

⁹¹ Act No. 468 of June 7, 2001, Denmark Criminal Code, *Borgerlig Straffelov*, Chapter 25, § 252; 3.

⁹² Executive Order No. 547 of June 15, 2001.

⁹³ Högsta domstolen, B4189-03, April 06, 2004.

⁹⁴ European Court of Human Rights (ECtHR), *Enhorn v. Sweden*, Application no. 56529/00, (January 25, 2005).

⁹⁵ Norwegian Penal Code of 1902, *Lov om straff (Straffelov)* strl.2005, § 237.

⁹⁶ Executive Order No. 1040 of November 8, 2011.

⁹⁷ Hovrätten över Skåne och Blekinge, B2152-13, October 29, 2013.

⁹⁸ See <https://lagen.nu/dom/rh/2015:2> (accessed 13/11/2024).

⁹⁹ HIV could be prosecuted under §§ 18 (intentional) and 20 (reckless) of the Offences Against the Person Act 1861 c. 100 (Regnal. 24 and 25 Vict).

¹⁰⁰ *R v Konzani*, EWCA Crim 706, 2005.

¹⁰¹ The general debate in criminal law was whether the presence of the infection canceled the consent, permitting to interpretate transmission as sexual assault/rape. *R v EB*, EWCA Crim 2945, CA, 2006.

Regarding PrEP, the European Medicines Agency (EMA) approval came in 2016, and only after intense social debates over the U=U campaign. The European response to the prevention revolution was slow, and a basis for the delay has been represented by the 2008 economic recession, which shifted the European HIV rights-based approach towards a risk management model, prioritizing resources on risk mitigation and cost-effectiveness and challenging HIV prevention implementation¹⁰². Member States' situations differ in specific criteria for access, targeted institutions for availability, and cost reimbursement due to the patchwork between full, partial, or no reimbursement of medications related to the health systems. Even in the countries that implemented PrEP, such as France and Germany, logistical and cultural barriers – prescription and in-person requirements and limited healthcare providers' knowledge or personal beliefs – still impede access¹⁰³. In contrast, countries like Poland, Bulgaria, Romania, and Hungary faced challenges incorporating PrEP into their healthcare frameworks due to conservative health policies. Despite structural barriers, states such as Austria, Czech Republic, Sweden, Finland, and Norway explicitly prohibited PrEP online purchases¹⁰⁴.

Nevertheless, following the numerous studies confirming the U=U campaign and the wave of the PrEP revolution, Section 237 of the Norwegian Code was finally amended in 2017, stating that when PLWHA has taken the «proper infection control measures» and «when the person who has been infected or exposed to the risk of infection has given prior consent» before sexual intercourse, there cannot be prosecutions. Therefore, disclosing a positive HIV status to a sexual partner equals consent¹⁰⁵. In 2018, the Swedish Supreme Court also dismissed a case of non-disclosure, finding that it was no longer required if a person is under effective treatment, meaning that when there is no real exposure risk, there is no crime¹⁰⁶.

3. HIV and HIV Prevention Digital Governmentality

As reconstructed, biomedical advancements have transformed HIV from a life-threatening illness into a manageable condition, prompting a shift in activism toward cyberspace to address disparities in access to preventive care and leading to legal changes in both the US and the EU. Nevertheless, proper from cyberspace, new legal issues were underscored.

3.1 Data, Desire, and Disease: the Grindr Transnational Saga

Digitalization is ever strictly entangled with datafication, and that was perfectly demonstrated by the “Grindr transnational saga”. In 2018, Grindr was first criticized for sharing HIV users' status – along with email, GPS, and phone – with third-party companies, leading to outrage from health and privacy advocates both in the EU and in the US¹⁰⁷. The study, conducted by the Norwegian nonprofit organization SINTEF¹⁰⁸ and initially transmitted by Swedish media and

¹⁰² SMITH 2016.

¹⁰³ AIDS Action Europe, Rapid Assessment on Access to PrEP in EU/EEA Countries, December 2022. Available at: <https://www.aidsactioneurope.org/en/publication/rapid-assessment-access-prep-eueea-countries> (accessed 2/10/2024).

¹⁰⁴ Denmark prohibited the online purchase of PrEP originating outside Europe. Pre-exposure prophylaxis for HIV prevention in Europe and Central Asia 2024, 2023 progress report. Available at: <https://www.ecdc.europa.eu/sites/default/files/documents/hiv-prevention-dublin-declaration-evidence-brief-2023.pdf> (accessed 2/10/2024).

¹⁰⁵ Amendment Act to the Norwegian Penal Code by Act, No. 90, 21 June 2017, §§ 237 and 237a.

¹⁰⁶ Högsta Domstolen, Case No. B 2441-17, June 7, 2018.

¹⁰⁷ For an overview of the first debates related to online dating-app and HIV regulations see MCCALLUM 2014; PAYNE 2018.

¹⁰⁸ <https://github.com/SINTEF-9012/grindr-privacy-leaks> (accessed 5/10/2024).

then spread in the European context, was further verified in the US by BuzzFeed News, globalizing the debate¹⁰⁹. In the wake of criticism, while LGBTQ+ activists underlined the platform's "betrayal", privacy advocates called for data privacy and confidentiality protection¹¹⁰.

3.1.1 *The US*

In 2017, before the Norwegian study results, Grindr was involved in its first data protection controversy in the US – not related to HIV – when a New York user sued the platform, claiming it enabled cyber-harassment by allowing his ex-partner to impersonate him with fake profiles that led to strangers harassing him in person. Despite a temporary restraining order (TRO) from the New York State Supreme Court, Grindr did not act. The case moved to federal court, where Grindr successfully argued immunity under Section 230 of the Communications Decency Act (CDA), which broadly shields platforms from liability for third-party content¹¹¹. The court found that Grindr could not be held responsible for failing to monitor, remove, or block content, and the claims were dismissed¹¹². The plaintiff's amended complaint introduced new claims, including product liability, negligent design, fraud, and promissory estoppel, alleging that the platform falsely advertised itself as safe. However, these claims were also dismissed on similar grounds of CDA immunity and insufficient evidence¹¹³. Then, also the appeal to the Court of Second Circuit was unsuccessful, and the case was dismissed¹¹⁴. Finally, a writ of certiorari was filed to the Supreme Court and denied in 2019¹¹⁵. The "Herrick legal saga" first underscored critical challenges at the intersection of platform immunity, user safety, and digital harassment, foreshadowing issues later amplified by the Norwegian findings.

The Norwegian report in the US initially raised concerns that Grindr's practices might violate California laws on unfair practices and privacy rights, especially given the company is headquartered in the State. In response to privacy and HIV data sharing, the American Civil Liberties Union (ACLU) urged consideration of potential violations under the state's new privacy laws¹¹⁶. Indeed, despite the general wave of HIV reforms, the report coincided with California's amendment of the Consumer Privacy Act (CCPA) of 2018, which imposed stricter duties on businesses collecting personal data. The CCPA mandates clear opt-out options, data deletion rights, and restrictions on data sales—requirements Grindr allegedly failed to meet¹¹⁷.

After the debate break during the COVID-19, at the federal level regarding HIV, the Repeal HIV Discrimination Act (2021) was finally enacted to «modernize laws and policies, and eliminate discrimination», underlining that «state and federal law does not currently reflect the *four decades* of medical advances and discoveries». Among the issues, the Act underlined that in most criminal regulations, the identity of the individual prosecuted «is broadcast through media reports, potentially destroying employment opportunities and relationships and violating the person's right to privacy»¹¹⁸. In the wake, other states such as Nevada fully repealed its HIV-

¹⁰⁹ Available at: <https://www.buzzfeednews.com/article/azeenghorayshi/grindr-hiv-status-privacy#.ypoJ48WoN> (accessed 5/10/2024).

¹¹⁰ Available at: <https://www.theguardian.com/technology/2018/apr/03/grindr-shared-information-about-users-hiv-status-with-third-parties> (accessed 5/10/2024).

¹¹¹ Communication Decency Act (CDA), 47 U.S.C. §230.

¹¹² *Herrick v. Grindr, LLC*, 17-CV-932 (VEC), S.D.N.Y. February 24, 2017.

¹¹³ *Herrick v Grindr, LLC*, No. 1:2017cv00932, S.D.N.Y. January 25, 2018.

¹¹⁴ *Herrick v Grindr LLC*, No. 18-396, 2d Cir. March 27, 2019.

¹¹⁵ *Herrick v Grindr, LLC*, No. 19-192, US Supreme Court, October 07, 2019.

¹¹⁶ Available at: <https://www.citizen.org/wp-content/uploads/CA-AG-Out-of-Control-NCC-1.14.20.pdf> (accessed 9/10/2024).

¹¹⁷ *California Consumer Privacy Act of 2018*, California Civil Code §§1798.100-1798.199.100, January 1, 2020.

¹¹⁸ Emphasis added. REPEAL HIV Discrimination Act of 2021, US HR1305, 117th Congress, April 28, 2021.

specific laws¹¹⁹. This shift was rooted in the understanding that HIV status disclosure and exposure criminalization meant both criminalizing prevention¹²⁰ and undermining privacy rights. In the same period, privacy concerns also led the CDC to broaden the narrative – referring to public health use of data and criminal laws – claiming to reinforce legal protections for confidentiality, security, and privacy, considering the possibility that such data could also be accessed by law enforcement and cyberattacks¹²¹.

Not much later, the Californian Grindr privacy debate renewed when the platform's former Chief Privacy Officer filed a lawsuit alleging wrongful termination after raising concerns about privacy violation practices¹²². His claims highlighted potential non-compliance with both federal and state whistleblower protection laws, including California Labor Code Section 1102.5, which safeguards employees who report violations of law¹²³. Nevertheless, this time the Grindr cases further moved beyond California's borders. Indeed, the Federal Trade Commission (FTC) was urged by the Electronic Privacy Information Center (EPIC) to investigate Grindr under Section 5 of the FTC Act, which prohibits unfair or deceptive trade practices. Specifically, EPIC contended that Grindr's privacy policy misrepresented the extent of data-sharing practices, thereby misleading consumers about their privacy rights¹²⁴. Furthermore, potential breaches of the Health Breach Notification Rule were cited, arguing that Grindr failed to notify users and the FTC of unauthorized disclosures of health-related data¹²⁵. Currently, the US Grindr debate remains unresolved.

3.1.2 The EU

In early 2020, according to a second Norwegian report, this time from the Norwegian Consumer Council (NCC), a significant privacy scandal emerged, reinvolving Grindr, other platforms such as Twitter and OKCupid, the mobile monetization platforms MoPub and Smaato, the American Telephone and Telegraph Company AT&T's, the American multinational technology AppNexus, the programmatic advertising technology company OpenX, and others. The report revealed in fact that these platforms were collecting and sharing sensitive user data – including HIV status, sexual orientation, drug use, political views, and even GPS locations and IP addresses – to a wide network of marketing companies and sometimes up to 135 third parties¹²⁶. Nevertheless, the attention focused especially on Grindr, since it was not Grindr's first controversy.

In early 2021, the Norwegian Data Protection Authority (DPA) issued a preliminary decision, fining Grindr for unlawfully sharing users' sensitive data with 19 third-party advertisers, including MoPub and AppNexus, which re-shared data with 170 and 4259 partners respectively¹²⁷. The DPA's final decision came in December 2021, concluding that Grindr's

¹¹⁹ Nevada SB 275, 2021.

¹²⁰ DORFMAN 2024.

¹²¹ CDC, HIV Criminalization Legal and Policy Assessment tool, 2021.

¹²² *De Jesus v Grindr*, Complaint for 23ST-CV1-13635, Ca. Super. Ct., June 14, 2023.

¹²³ California Labor Code LAB, §1102.5 Whistleblower protection, as amended by SB No. 497 Ch. 612, October 8, 2023.

¹²⁴ Electronic Privacy Information Center (EPIC), *In re Grind LLC, Complaint and Request for Investigation, Injunction, Penalties, and Other Relief*, Federal Trade Commission (FCT), October 4, 2023.

¹²⁵ Health Breach Notification Rule, § 13407 of the American Recovery and Reinvestment Act of 2009, 42 U.S.C. 17937. The rule requires vendors of personal health records and the related entities not covered by the Health Insurance and Portability Act (HIPAA) to notify the FTC, individuals, and, in specific cases, the media of a breach of personally identifiable health data.

¹²⁶ Available at: <https://www.forbrukerradet.no/side/new-study-the-advertising-industry-is-systematically-breaking-the-law/>; <https://www.forbrukerradet.no/side/complaints-against-grindr-and-five-third-party-companies/> (accessed 4/10/2024).

¹²⁷ Available at: <https://blog.runbox.com/2024/08/the-grindr-case-illustrates-norwegian-authorities-fight-against-misuse-of-personal-information/> (accessed 4/10/2024).

consent mechanisms did not meet the legal requirements under the GDPR.

While Grindr appealed the Norwegian decision, in July 2022, the UK Information Commissioner's Office (ICO) issued a warning to Grindr regarding its processing operations, citing violations of the UK GDPR¹²⁸. In 2024, the law firm Austen Hays issued a collective claim against the app in England and Wales for breaching the UK's GDPR¹²⁹, and the High Court granted an anonymity application for the 670 Grindr users' claimants¹³⁰. While the court decision remains pending, in July 2024, the app finally lost its challenge in the Oslo District Court¹³¹.

The Norwegian ruling sets a strong precedent for companies practicing commercial surveillance, underscoring that unrestricted data collection and sharing do not go unchallenged and that the digital advertising industry must take steps to uphold and protect both essential consumer rights and individual fundamental rights. Although the importance of the Norwegian decision, as for the US, also the European Grindr debate has not ended.

Conclusion

As reconstructed, both in the US and the EU, regulatory approaches continue to be rooted in the stigmatization of HIV, while HIV social construction continues to be shifted by activists' engagement. However, with the expansion of digital platforms and the global digital market, HIV digitalization is no longer solely driven by the "parrhesiastic attitude" of activists, but also by broader technological and economic forces.

While cyberspace has played a crucial role in enhancing HIV networking, information dissemination, and prevention, it currently raises significant concerns. First, although digitalization has historically improved HIV care and continues to do so, at present, particularly concerning PrEP, it also introduces risks associated with online misinformation and potentially harmful content. Moreover, digitalization has impacted individuals' privacy, confidentiality, and security, as healthcare providers, insurers, and tech companies increasingly share data for various purposes. Instances of cyber-harassment further underscore the real-world consequences of digital exposure. Additionally, the ongoing transnational legal issues related to Grindr underscore broader regulatory gaps regarding tech platforms that handle sensitive data, raising urgent questions about consent standards, transparency in data practices, and the enforcement of both US and EU regulatory frameworks.

The biases behind the traditional HIV legal approaches and the absence of updated protections exacerbate vulnerabilities, particularly given that online privacy breaches could still lead to discrimination, legal repercussions, and social harm. Thus, addressing these challenges requires more than repealing scientifically outdated laws. Indeed, it demands both platforms and public institutions to "intersectionalize" privacy, security, confidentiality, health, and non-discrimination, ensuring that PLWHA and those under prevention can fully understand and control how and what types of their data are used and for what purposes are shared. This entails adopting more stringent data protection, providing clear and accessible consent mechanisms, and implementing safeguards to protect health while preventing misuse or discrimination. For

¹²⁸ Available at: <https://www.datatilsynet.no/en/news/aktuelle-nyheter-2023/record-fine-grindr-confirmed/>; <https://www.datatilsynet.no/en/news/aktuelle-nyheter-2022/datatilsynet-har-mottatt-klage-pa-overtredelsesgebyr-i-grindr-saken/> (accessed 9/10/2024).

¹²⁹ Data Protection, Privacy and Electronic Communications (Amendments etc) (EU Exit) Regulations 2019.

¹³⁰ Available at: <https://www.austenhays.com/claims/grindr-breach-of-privacy-investigation/grindr-claim-timeline/>; <https://www.judiciary.uk/judgments/various-claimants-v-grindr-inc-and-another-anonymity-order/> (accessed 10/10/2024).

¹³¹ Oslo Tingrett, *Grindr LLC v the State*, No. 23-160384TVI-TOSL/04, July 1, 2024.

instance, PrEP platforms that facilitate access to preventive medication should guarantee not only safe drugs and secure transactions, but also data protection and non-discriminatory policies. Similarly, apps designed to help users manage appointments and medication adherence must prioritize user confidentiality and consent transparency. Lastly, cases like Grindr's unauthorized sharing of users' HIV status with third-party advertisers highlight the urgent need for stricter oversight and accountability in the digital market, preventing the HIV-related information exploitation for commercial gain and ensuring individuals' safety and privacy.

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