HIV/AIDS: AN INTERSECTION BETWEEN PUBLIC HEALTH AND DATA PROTECTION LAWS

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ABSTRACT

This research paper delves into the critical intersection of HIV/AIDS, human rights, and public health strategies. It presents the conundrum of AIDS which lies in the counterintuitive notion that safeguarding the rights of vulnerable populations, rather than isolation, is pivotal for effective HIV control. Upholding confidentiality emerges as a lynchpin in this approach, protecting individual's rights to privacy and empowering them to disclose their HIV positive status to their partners which ultimately benefits public health. Further the paper discusses the negative effects of involuntary disclosure of HIV positive status resulting in severe consequences for individuals, from denial of opportunities to social stigmatization. These negative effects highlight the necessity of adopting a rights-based, confidential approach in the global fight against HIV/AIDS. Further this paper sheds light on the provisions of HIV/AIDS Act, 2017, emphasizing its role in balancing the public interests and confidentiality. It outlines provisions for partner notifications, responsibilities of those in close contact with HIV positive individuals and establishes a grievance redressal mechanism. The research paper also addresses concerns regarding the confidentiality of health data of patients in the digital age, emphasizing the need and requirement for precise legal frameworks.

KEYWORDS- HIV/AIDS ACT, CONFIDENTIALITY, INFORMED CONSENT, DATA PROTECTION, DIGITAL HEALTH TECHNOLOGIES, PRIVACY BY DESIGN

INTRODUCTION

In India, an estimated 2.14(1.59-2.84) million individuals are currently living with HIV infection which represents the third largest population of People living with HIV/AIDS (PLHIV) in any country globally.[1] Notably, the national HIV prevalence among adults in India was reported at 0.22% in 2017, showing a consistent decline in recent years. However, it's crucial to acknowledge that this overall national trend conceals considerable regional, state, and district-level disparities within the country.[2] India's HIV epidemic is primarily fueled and sustained by high-risk subpopulations, such as female sex workers (FSW), men who have sex with men (MSM), injecting drug users (IDU), and bridge populations, with subsequent transmission to the general population.[3]
In 1992, India initiated the National AIDS Control Program (NACP) to address the prevention and management of HIV/AIDS. The NACP places a significant emphasis on district-level implementation of prevention and control strategies, tailoring interventions based on the specific

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[1] Ministry of Health and Family Welfare, *India's HIV estimations 2017, Technical Report* (2017).

[2] *id.*

[3] Padma Chandrasekaran, Containing HIV/AIDS in India: the unfinished agenda, THE LANCELET, Aug. 2021, at 508-521.

vulnerabilities and the magnitude of the HIV burden within each district.[4] Despite sustained efforts in HIV control spanning over two decades, certain districts in India continue to report persistently high HIV prevalence.[5]

Research shows that the districts with a large population size, high population density, more urbanization, higher proportion of population in the reproductive age group, higher sex ratio, better standard of living and higher mean marriage age were more likely to have consistently high HIV prevalence levels in India.[6] We found that higher knowledge levels about the role of condoms for HIV prevention as well as the use of condoms at the population level were associated with lower HIV levels in the districts.[7]

The separation of individuals from their families, the proliferation of the sex trade, delayed marriage, and increased economic opportunities stemming from employment have collectively created an environment conducive to engaging in sexual encounters with multiple partners, including both commercial and non-commercial liaisons.[8] These circumstances, exacerbated by limited access to information regarding HIV prevention and the availability of condoms, can significantly elevate the risk of engaging in unsafe sexual practices and, consequently, the likelihood of HIV transmission.[9] Furthermore, densely populated urban areas, where high-risk groups such as female sex workers (FSW) and men who have sex with men (MSM) are known to cluster, may further exacerbate the HIV epidemic in these districts.[10]

This research paper explores the intricate intersection of HIV/AIDS, human rights, and public health strategies in India. It underscores the intriguing paradox inherent in the AIDS epidemic: the idea that safeguarding the rights of vulnerable populations, rather than isolating them, is central to effective HIV control. Within this context, the critical role of confidentiality comes to the forefront, not only protecting individuals' privacy rights but also enabling them to make informed choices about disclosing their HIV-positive status to partners, ultimately benefiting public health. The ramifications of involuntary disclosure of one's HIV-positive status are profound, often resulting in dire consequences for individuals, ranging from the denial of opportunities to social stigmatization. These adverse effects underscore the pressing need for adopting a rights-based, confidential approach in the global battle against HIV/AIDS.

This paper delves into the key provisions of the HIV/AIDS Act of 2017, shedding light on its role in striking a balance between the interests of the public and the imperative of maintaining confidentiality. It outlines the stipulations for partner notifications, delineates the responsibilities of those in close contact with HIV-positive individuals, and establishes a grievance redressal

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[4] District AIDS Prevention and Control Units (DAPCU) Guidelines (November 2012).

[5] *id.*

[6] Rajneesh Kumar Joshi, *Determinants of consistently high HIV prevalence in Indian Districts: A multi level analysis*, PLOS ONE (May 7, 2019).

[7] Jessica M. Perkins, *Patterns and Distribution of HIV among adult men and women in India*, PLOS ONE (May 21 2009).

[8] Marissa Becker, *Prevalence and determinants of HIV infection in South India: a heterogeneous, rural epidemic*, AIDS (March 30, 2007).

[9] Ranjan Roy, *Measuring the Multidimensional Knowledge Deprivation of HIV/AIDS: A new approach with Indian Evidence its Magnitude and Determinants*, JOURNAL OF BIOSOCIAL SCIENCE (July 15, 2011).

[10] Robert Bollinger, T*he human Immunodeficiency Virus Epidemic in India: Current Magnitude and Future Projections*, MEDICINE (March, 1995).

mechanism. Furthermore, this research paper addresses the growing concerns surrounding the confidentiality of patients' health data in the digital age, highlighting the urgent need for precise and robust legal frameworks to ensure that the rights of individuals living with HIV are preserved while safeguarding public health in an ever-evolving information landscape.

RIGHTS BASED HIV INTERVENTION

Consider a scenario, where a person after falling sick, suspects having HIV virus due to their recent sexual practices or as a result of possible exposure. Would this person seek medical attention knowing that their health status will be revealed potentially to the world? Especially when they are aware of the stigma that follows HIV positive individuals? Or would this person try to treat themselves symptomatically by self-medicating? Would they look for authentic health advice from a healthcare system they do not trust to keep their health data confidential? Or would they try to avoid vital changes in behavior such as practicing safe sex?

The scenario depicted above showcases strategies that were originally considered as the most effective means of addressing HIV/AIDS. These approaches involved identifying individuals by disclosing their health status to others, with the aim of isolating them and modifying their behavior. In certain regions of the world, lawful measures are still the recommended approach for controlling the spread of HIV/AIDS.[11]Historically, the policy response in relation to HIV/AIDS has always been filled with panic and suppression along with an urge to hide and isolate those who are infected so that they are unable to infect the uninfected. Some regions still advocate punitive measures as a means to control HIV/AIDS. For instance, in the United States, numerous states have enacted 'HIV exposure' laws, making it illegal for individuals with HIV to engage in sexual intercourse without disclosing their status, even when using condoms. These laws fail to consider factors that influence transmission risk, such as condom usage or adherence to antiretroviral therapy. Many arrests and prosecutions have occurred under these laws, which has led to the marginalization of populations, including people of color and sex workers. However, there is no evidence to support the idea that these laws reduce HIV transmission or encourage individuals to disclose their HIV status or seek testing. [12]

As stated above, one of the concerns is the legal criminalization of vulnerable populations. Many individuals who are at a high risk of HIV transmission belong to communities that are targeted by legal regulations, including sex workers, gay men, people who use drugs, and transgender individuals. The Global Commission on HIV and the Law has highlighted that in countries like South Africa and the Caribbean, where same-sex relationships are considered illegal, the prevalence of HIV among men who have sex with men is significantly higher compared to areas where such punitive laws are absent.[13] In places where a rights-based approach to HIV/AIDS has been established, ensuring the protection and respect of individual rights, it has led to a reinforcement of these rights and promoted an inclusive public health strategy that encourages individuals to seek healthcare.

A striking example of a successful rights-based approach can be observed in Sonagachi, Kolkata, where the Durbar Mahila Samanway Committee (DMSC) and its self-regulatory boards (SRBs)

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[11] Global Commission on HIV and the Law, *Risks, Rights and Health* (July 2012).

[12] Stephanie Pappas, *HIV laws that appear to do more harm than good*, APA, Oct. 2018, at 32.

[13] *id.*

have made remarkable strides. This pioneering HIV prevention initiative was built on the belief that sex workers themselves are in the best position to address their community's needs through a rights-based strategy that empowers and actively involves them in improving healthcare in their community. The initiative discussed here is the Sonagachi HIV Intervention Program(SHIP), which was launched in 1992. SHIP's approach was characterized by three key components: provision of health services (including HIV treatment), information, education and communication and condom distribution.[14] Crucially SHIP prioritized the empowerment of sex workers, respecting their profession and improving their working condition. This approach fostered trust and mutual respect between the community and SHIP staff. Moreover, SHIP's impact extended beyond behavioral change, addressing broader social power dynamics within the sex industry.[15]It led to the establishment of the Durbar Mahila Samanwaya Committee (DMSC), a forum for sex workers, which expanded its services across red light districts. Despite facing challenges from within the industry and societal resistance, SHIP's innovative approach enabled negotiation and empowerment, promising long lasting benefits for sex workers and society as a whole.[16] Their collective efforts and advocacy for their rights yielded exceptional health and social benefits. Over the course of fifteen years, condom usage within the brothels increased from under 3% to 87%, syphilis rates dropped from 25-30% to less than 1%, and HIV prevalence stabilized at 5%, a significant improvement compared to the over 50% rates observed in other major Indian cities.[17] Furthermore, the SRBs established regulations for entry into sex work, identified and addressed abuses, and took action when the presence of underage females or coercion in the sex industry was suspected. These endeavors led to a significant reduction in the proportion of minors engaged in sex work in Sonagachi, decreasing from 25% to 2% between 1992 and 2011, and also resulted in an increase in the median age of sex workers from twenty-two to twenty-eight years.[18]

THE AIDS CONUNDRUM

From the very outset, it was popularly believed that the most effective way to limit the spread of the virus was through coercive approaches such as mandatory HIV testing, disclosure of HIV-positive individuals publicly, and their subsequent isolation.[19] This approach became evident in India when Goa amended its Public Health Act in 1987. Under this law, individuals suspected of having HIV were subject to compulsory testing and immediate isolation.[20]

Jonathan Mann, epidemiologist and head of the WHO's Global Program on AIDS was the first to shed light on the spread of HIV in communities of weaker social status. Mann argued that women of color, women of Africa and gay men of North America were the people most susceptible to HIV. He contended that AIDS was more than just a medical condition; it was a societal ailment that thrived in the presence of oppression, gender inequality, economic disenfranchisement, and violence. Effectively addressing this crisis would only be possible if those who were most affected

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[14] DURBAR MAHILA SAMANWAYA COMMITTEE ('DMSC'), *DMSC HIV/STD Intervention Project,* (Feb. 26, 2011) available at https://nswp.org/resource/member-publications/dmsc-hivstd-intervention-project.

[15] *id.*

[16] *id.*

[17] Smarajit Jana, *Combating Human Trafficking in the Sex Trade: Can Sex Workers Do It Better?* JOURNAL OF PUBLIC HEALTH, Dec. 2014, at 622-628.

[18] *id.*

[19] The Goa, Daman and Diu Public Health Act, 1985, No. 25, Acts of Legislative Assembly of Goa, Daman and Diu, 1985.

[20] *id.*

were empowered and guaranteed their fundamental human rights.[21] Enforcing a policy that further penalized these individuals was not the appropriate means to encourage them to adopt health-seeking behaviors. On the contrary, such punishment would only exacerbate the existing stigma. Furthermore, Justice Michael Kirby of Australia, a prominent figure in the HIV movement, emphasized that in order to effectively combat the spread of HIV, it was imperative to uphold and safeguard the rights of those who were most vulnerable to the virus.[22]

This was the conundrum of AIDS – the counterintuitive notion that the prevention of HIV's spread required empowerment and the protection of the rights of marginalized populations, rather than isolation and repression. Implicit in this approach was the belief that safeguarding the human rights of those already affected by HIV/AIDS or susceptible individuals were inherently sacred. In addition to upholding human rights, this approach also served the broader public health goal of disease control.

When healthcare institutions provide de-stigmatized and empathetic services and accurate health advice, they make sure that people who are exposed to and are at the risk of being exposed to, access their services. Such methodology of empowerment assures no discrimination, respect for autonomy and integrity of every individual along with the protection of confidential information on a person’s health. Among various factors, the guarantee of keeping one's HIV status confidential is pivotal in the context of an effective public health strategy. Through unprejudiced and essential counseling services, individuals are motivated to disclose their HIV status to sexual partners, ultimately aiming to protect everyone.

CONFIDENTIALITY AND HIV RESPONSE

Confidentiality is deeply rooted in the fundamental rights safeguarded by the Indian Constitution. The Constitution’s Article 21 shields individuals from actions of the state that encroach upon their right to life and liberty, except as permitted by the law. This right to personal liberty has been interpreted to encompass the right to privacy. In the case of *Justice K.S. Puttaswamy v. Union of India*, the Supreme Court emphatically articulated the right to privacy as enshrined under the Article 21 of the Constitution of India.[23] During this legal proceeding, the court emphasized that the concept of confidentiality is closely associated with and stems from the fundamental right of privacy.[24]

The concept of confidentiality of information primarily arises within fiduciary relationships, which are inherently unequal. In these relationships, one party receives information from another that would typically remain undisclosed but is shared because of the unique expertise or role they possess. Examples of such relationships include doctors in relation to their patients and lawyers with their clients.[25] The idea of confidentiality as a legal principle evolved over time through court rulings and in various contexts unrelated to HIV.[26] These legal interpretations refined our understanding of medical confidentiality and contributed to the development of approaches that were subsequently incorporated into HIV-related policies. Extensive documentation and research

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[21] Michael Kirby, *Human Rights and the HIV Paradox,* THE LANCELET, Nov. 1996, at 1217-1218.

[22] *id.*

[23] Justice K.S. Puttaswamy v. Union of India, (2017) 10 S.C.C 1

[24] *id.*

[25] The Indian Evidence Act, 1872, §129.

[26] THE LAWYERS COLLECTIVE, LEGISLATING AN EPIDEMIC: HIV/AIDS IN INDIA (2003).

have indicated that the involuntary disclosure of one's HIV-positive status has often led to discrimination, manifesting in various ways such as job denial, refusal of healthcare services, and societal stigmatization.[27] Such disclosures had dire and heartbreaking consequences, ranging from violent harm to cruel isolation, neglect, and even expulsion from educational institutions.[28]

The concepts of privacy and confidentiality are deeply ingrained in medical practice. The modernized Hippocratic oath emphasizes that a physician will honor the privacy of their patients, understanding that the patients share their issues in confidence, not for the world to know.[29] Additionally, the Indian Medical Council of professional conduct, etiquette and ethics, Regulations of 2002, which regulate healthcare practice in India, dictate that a doctor must not divulge a patient's confidential information unless it is required by law or when the doctor believes that a 'responsibility to society necessitates the use of knowledge obtained in confidence as a physician to safeguard a healthy individual from exposure to a communicable disease. In such cases, the physician should behave in the same way as they would expect someone to behave towards a member of their own family in similar circumstances'.[30] Concerning HIV, the National AIDS Control Program has acknowledged the vital importance of maintaining confidentiality as a cornerstone of an effective response to the epidemic.[31]

DISCLOSURE OF HIV STATUS

In a brief yet contrary move from the principles of a rights-based approach to HIV control, a ruling by the Indian Supreme Court in the case of Mr. X v. Hospital Z had significant repercussions for the confidentiality of an individuals' medical status.[32] This legal case originally emerged in a consumer court as a service breach claim filed by Mr. X, who alleged that the hospital's pathology department, where he had been diagnosed as HIV-positive, had violated his confidentiality by disclosing his status to his family members and others. The case rose to the Supreme Court, which ruled to suspend the right of people living with HIV to marry. While the court acknowledged the right to privacy and the ethical obligation of physicians to maintain the confidentiality of patient information, it invoked the Medical Council of India's Code of Medical Ethics, which allowed for exceptions to confidentiality in cases involving public interest or health risks to others. In this context, the court determined that the disclosure of Mr. X's HIV status was defended since his partner's health was at stake. The Court also mentioned that an individual living with HIV who marries and subsequently infects their spouse could face legal liability under Sections 269 and 270 of the Indian Penal Code (IPC), which pertain to those who commit a negligent and malicious act that is "likely to spread a disease that is life threatening."[33] However, in a re-evaluation of this judgment in 2002, the Supreme Court acknowledged that Mr. X's rights remained intact despite the revelation of his health status in that particular case. Nevertheless, the Court withdrew its own earlier observations concerning the right to marry, privacy, confidentiality, and criminal liability.[34] While the Court's findings and conclusions regarding Mr. X's rights may be subject to scrutiny - as he had not indicated any intention of withholding his health status from a potential spouse -

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[27] *supra*, note 26.

[28] *id.*

[29] Rachel Hajar, *The Physician's Oath: Historical Perspectives,* HEART VIEWS, Dec. 2017, at 154-59.

[30] Indian Medical Council (Professional Conduct, Etiquette and Ethics) Regulations, 2002, Reg. 2.2.

[31] *id.*

[32] Mr. X v. Hospital Z, (1998) 8 S.C.C. 296.

[33] The Indian Penal Code, 1860, §269.

[34] Mr. X v. Hospital Z, (2003) 1 S.C.C. 500.

there might be legitimate situations in which the disclosure of one's HIV status becomes necessary, even though confidentiality remains a paramount concern. However, it's crucial for healthcare workers or counselors to make such a decision by carefully considering the fine balance between two significant public interests, as initially outlined in the case of X v. Y. On one side, there is the public interest in upholding confidentiality, while on the other, there is the public interest in ensuring that others are informed to safeguard themselves. Crucially, this perspective illustrates that rights-based approaches to HIV do not create a paradox between individual rights and societal rights. Instead, they promote the idea of safeguarding individual rights while also strengthening public health and broader societal rights.

A notable case that brings to light the complexities of these issues is the case titled as *Tarasoff v. Regents of the University of California*.[35] Though unrelated to HIV, in this case, a university student named Prosenjit Poddar had a brief romantic involvement with fellow student Tatiana Tarasoff. After their relationship ended, Tarasoff started seeing another man, which deeply upset Poddar. He sought therapy with a psychologist, Dr. Moore, and during their final therapy session, Poddar expressed his intention to harm an unnamed female, who was clearly identifiable as Tarasoff. Dr. Moore, concerned for Tarasoff's safety, wrote to the campus police and sought assistance in having Poddar confined to a mental hospital. After an interview, the police determined that Poddar was rational and released him with a warning to stay away from Tarasoff. Subsequently, the hospital management withdrew Dr. Moore's letter and the request for Poddar's confinement, however it was found out that Poddar went on to kill Tarasoff. Tarasoff's parents filed a lawsuit against the university and Dr. Moore, contending that they should have been informed about the threat Poddar posed to their daughter. This case raised the question of whether the doctor had a duty to disclose the threat Poddar presented to Tarasoff, even considering the confidentiality of their relationship.

In reaching its verdict, the court carefully balanced the two public interests that required consideration: the patient's right to privacy and the need to warn another individual of an immediate risk. The court determined that when a doctor has, or should have reasonably determined, that a patient poses a serious danger, there exists a duty to take reasonable steps to protect the potential victim.[36] Furthermore, any disclosure should be made discreetly and in a manner that upholds the patient's privacy to the greatest extent possible while preventing the impending harm.[37]

The legal reasoning adopted in the case mentioned above has given rise to significant conditions that have influenced disclosure practices in both mental health and HIV contexts. These conditions include, firstly, the need for a determination made in accordance with professional standards that is considered reasonable; secondly, the seriousness of the danger must be established; thirdly, the individual at risk must be identifiable (and not relied on a common concern of harm being caused to an unidentified individual); and fourthly, the disclosure should be made in a manner that is as narrow as possible while still addressing the potential threat.

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[35] Tarasoff v.Regents of the University of California, 17 Cal.3d 425.
[36] *supra,* note 35.
[37] *id.*

HIV/AIDS ACT OF INDIA

India in 2017, passed the India's HIV/AIDS (Prevention and Control) Act more commonly known as the HIV/AIDS Act with the main objective for its enforcement being the balancing of the public interests to disclose AIDS or not to do so in relation to the *Tarasoff* reasoning, which is further influenced by the AIDS paradox. Section 8 of the Act clearly stipulates that no person shall be forced or compelled to reveal their HIV status barring one exception i.e. if the court orders such information to be disclosed for the purpose of adjudicating disputes before it.[38] The Act also precisely lays down the law relating to the disclosure of status of HIV to a third party by another person and stipulates that in case the HIV status of a person is disclosed "in confidence or in relationship of a fiduciary relationship", the same can only be imparted to a third party after obtaining consent in writing or recording the receipt of such consent in writing. In addition the provision deals with certain exceptions where consent to disclose as mentioned above is not required.[39]

One of the exceptions provided in Section 8 regarding consent and third party disclosures is in cases of partner notification and this ground has been dealt with in detain under Section 9 of the HIV/AIDS Act. It provides by giving a physician or a counselor sole authorization to disclose the HIV status of a person (who are directly under their care) to their partner.[40] However the act lays down several conditions which have to be satisfied before such disclosure.[41]

Moving forward, Section 10 of the Act focus on the responsibility of the persons residing with the people who have tested positive for HIV and to maintain a degree of care. This requires such persons to be accordingly counseled and make sure that they are aware of the nature of HIV and its ways of transmission enabling them to take steps to prevent the transmission with the help of reasonable precautions. Such precautions might include use of condoms and using clean needles or by informing their partners about their HIV status in advance.[42]

The HIV Act further provides for a grievance redressal mechanism in the case of violation of rights under the act, including a breach of confidentiality which is impermissible as per the provisions of the Act. It is important to mention that the act was introduced in the backdrop of a judicial system which is inaccessible and overburdened leading to long delays for the resolution of disputes. However, in the case of HIV, the need of the hour was a rapid resolution of disputes due to the nature of the syndrome and the same was put into effect with the help of Section 21 of the Act which provides for grievance redressal to be available institutionally for corporations or establishments having more than a hundred persons, and in case of healthcare establishments comprising of more than 20 persons.[43] The compliance of these provisions is ensured by making it mandatory for these establishments to appoint a complaint officer tasked with resolution of complaints within 7 days of the receipt of the complaint. It is further provided that if the complaint pertains to discrimination, the officer is required to resolve the same on the same day as the receipt

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[38] HIV/AIDS (Prevention and Control) Act, 2017, §8.
[39] *id.*
[40] HIV/AIDS (Prevention and Control) Act, 2017, §9.
[41] *id.*
[42] HIV/AIDS (Prevention and Control) Act, 2017, §10.
[43] HIV/AIDS (Prevention and Control) Act, 2017, §21.

of the complaint.[44] Furthermore, the Act stipulates necessary training for the complaints officer for proper compliance with the provisions of the Act, including care, support and treatment, information on prevention, gender identity and sexual orientation, sex work and drug use and discrimination and the stigma associated with HIV.[45]

While the procedure in relation to make and receive complaints is provided in the HIV/AIDS (Prevention and Control) Rules, 2018, there is a requirement to protect the complainant by maintaining confidentiality about his identity, if the same is requested by the complaints officer.[46] The rules provide the manner of protection of identity, including the provision relating to pseudonyms and a provision against revealing the identity of the complainant in any form of publication. Further the provision for suppression of the identity in any court proceedings under law is also stipulated in the HIV Act, on the request of a party to the court proceedings, who falls under the definition of a “protected person”.[47]

The act in addition to providing remedies at the localized institution level, also stipulates pre-court dispute resolution with the facilitation of state appointed ombudsperson.[48] The duties of such a person involve investigation of complaints with regards to discrimination and various health services like confidentiality, informed consent and a safe working environment. Further provisions for a time bound resolution of disputes are also specified in relation to the ombudsperson.[49] The aim of the HIV act, therefore, is to provide a faster and more accessible grievance redressal mechanism to complainants. It is very unfortunate that very little steps have been taken for the effective implementations of the provisions of this Act.[50]

India has adopted a finely balanced legislative approach to confidentiality in reference to HIV. While for the implementation of a successful rights based approach, it is important that confidentiality is ensured, however, the HIV/AIDS Act contains a built- in reasoning and provisions which allow for disclosure in specified manners which not only protect the health of other persons but also maintains the necessity of confidentiality. It aims to cater to both the individual as well as the priorities of public health. There is little evidence however of the effective real world implementation of these provisions. The Act places a duty upon the ombudsperson to provide reports regarding the nature and number of complaints received, the action taken on such complaints and the orders to the government in this regard bi-annually, coupled with publishing the required information on the official website and further forwarding a copy to the Central Government, at present it is not even clear whether the state governments have appointed officers to the post or not.[51]

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[44] HIV/AIDS (Prevention and Control) Rules, 2018, Rule 10.

[45] HIV/AIDS (Prevention and Control) Rules, 2018, Rule 9.

[46] HIV/AIDS (Prevention and Control) Rules, 2018, Rule 13.

[47] HIV/AIDS (Prevention and Control) Act, 2017, §34.

[48] HIV/AIDS (Prevention and Control) Act, 2017, Chapter X.

[49] HIV/AIDS (Prevention and Control) Act, 2017, §26.

[50] Tarun Bathini, *Two Years Since HIV and AIDS Act Was Notified, Govts Have Done Little to Implement It*, THE WIRE, Sept. 10, 2020.

[51] HIV/AIDS (Prevention and Control) Act, 2017, §29.

CONFIDENTIALITY OF HEALTH DATA IN THE DATA TECH AGE

The utilization of digital health technologies is deemed a crucial component in the effort to eradicate HIV/AIDS, within the broader framework of achieving universal health coverage as a public health goal. In the Political Declaration on HIV and AIDS, with the aspiration to put an end to AIDS by 2030, member states of the United Nations pledged to harness the potential of digital technologies to advance HIV responses while honoring their human rights commitments.[52] Digital interventions are already playing an instrumental role in the global HIV response, serving various functions such as prevention, ensuring treatment adherence, and facilitating surveillance.[53]

However, alongside the potential benefits offered by emerging digital technologies, significant human rights challenges have been recognized, including the potential violation of rights related to confidentiality, and non-discrimination. The United Nations Resolutions and Political Declarations pertaining to Digital Health[54] states that, while supporting public health objectives, in order to align with human rights obligations, the adverse impacts associated with digital health technologies should be reduced by:

a) Implementing a comprehensive data protection law to regulate the collection, processing, and sharing of health data.
b) Ensuring that health systems are prepared to meet the demands of digital and technological infrastructure, which includes training for healthcare personnel, and the establishment of robust data security governance measures.
c) The deployment of digital health tools should be executed in a firmly rooted manner and guided by established obligations related to the rights to health and privacy, alongside ethical equity.

In the Supreme Court of India in the case of Justice *K.S. Puttaswamy v. Union of India*[55], issued a unanimous ruling reaffirming that the right to privacy, which includes the privacy of medical data, is a fundamental right. Furthermore, the court established guidelines for assessing the constitutionality of any action that encroaches upon privacy:

a) The action must be authorized by law.
b) The law must serve a legitimate purpose.
c) The proposed action must have a rational connection to the intended purpose.
d) The option should be the least restrictive one.
e) The law must include safeguards against potential abuse.

The court also realized that the proliferation of technology and widespread digitization have introduced new threats to informational privacy from both state and non-state entities. Consequently, it called for the enactment of a comprehensive data protection law to address these concerns.

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[52] United Nations General Assembly, Political Declaration on HIV and Aids: Ending inequalities and getting on track to end Aids by 2030 (2021), https://www.unaids.org/sites/default/files/media_asset/2021_political-declaration-on-hiv-and-aids_en.pdf.

[53] J.Simoni & K.Horvath, *Opportunities and Challenges of Digital Technology for HIV Treatment and Prevention*, CURRENT HIV/AIDS REPORTS, Sept. 2015, at 437-440

[54] World Health Assembly Resolution, *Global strategy on digital health 2020-2025*, WHA 71.7 2018 (2018)

[55] *supra*, note 23.

Entities responsible for maintaining records of a person's HIV-related information are mandated to implement data protection measures. These measures include the establishment of protocols for safeguarding information from unauthorized disclosure, procedures for accessing this information, the implementation of security systems to protect stored information in any format, and mechanisms to ensure accountability and liability for individuals within the organization.[56] Comprehensive data protection laws and specialized regulations within the health sector would govern the collection, storage, processing, and sharing of sensitive health data, including information related to HIV status. This becomes particularly imperative in light of the increasing reliance on information and communication technology (ICT) and the growing utilization of digital health tools, such as electronic health records (EHRs), telemedicine, and disease surveillance systems, all of which play essential roles in advancing public health objectives.

During the initial COVID-19 peak, the first wave, the Indian government launched National Digital Health Mission (NDHM) and issued a policy, Health Data Management Policy (HDMP) and further led to the publication of a policy document to guide its implementation. The HDMP permits numerous entities to collect private health data of people and set privacy standards for sensitive health data. The HDMP, being a non-statutory executive directive, presents constitutional concerns regarding the digital health implementation. The absence of a legal framework at the time of writing implies a misalignment of priorities, with the policy being implemented prematurely. To ensure the protection of fundamental rights, it is imperative that a legal framework precedes the execution of policies like the HDMP.

Conversely, the NDHM endeavors to digitize patient health records through Electronic Health Records (EHRs) linked to a unique health identity (UHID), which could be established using government-issued identity cards, preferably Aadhaar. These EHRs would encompass sensitive information, including a person's HIV status, and serve as electronic representations of a patient's personal information and detailed medical history.[57] EHRs would contain all the confidential health data of patients at a single source, shareable at the click of a button between different healthcare providers as well as multiple private and public entities via numerous linkable devices and platforms. The expanding number of access points to sensitive health data that transpires from EHRs is a serious concern to patients and brings in new challenges to confidentiality, privacy and security of the health information.[58]

Electronic systems must incorporate technological mechanisms to safeguard data confidentiality and privacy, in compliance with existing privacy laws such as the Puttaswamy ruling, confidentiality laws like the HIV Act, and the internationally recognized principle of 'privacy by design'. However, the HDMP exhibits shortcomings in ensuring the confidentiality of sensitive health data.[59] For instance, it does not explicitly incorporate 'data masking,' a technique crucial for

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[56] HIV/AIDS (Prevention and Control) Act, 2017, §24.

[57] Mudit Kapoor, *Unique Health Identification and Aadhaar: A case for mandatory linkage*, IDEAS FOR INDIA (Dec. 23, 2016), https://www.ideasforindia.in/topics/governance/unique-health-identification-and-aadhaar-a-case-for-mandatory-linkage.html

[58] Bernd Blobel, *Authorisation and Access Control for Electronic Health Record Systems*, INTERNATIONAL JOURNAL OF MEDICAL INFORMATICS, Jan. 2004, at 251-257.

[59] Shefali Malhotra, *Analysing the NDHM Health Data Management Policy* (2021), https://ea51c4f6-3257-4b64-b189-d18d2b68e428.filesusr.com/ugd/bfda9b_14f8cf90a45b48958b4209442e8db9f8.pdf

maintaining the confidentiality of sensitive medical information. This hinders individuals from controlling the sharing of their data with other healthcare providers, as may be necessary for their healthcare, and fails to align with the confidentiality principles outlined in the HIV Act. Additionally, the HDMP lacks clarity on 'purpose limitation,' a fundamental element of privacy and data protection standards. This necessitates that personal data must be collected and processed exclusively for specific and legal objectives, with a time limitation, and should not undergo processing that is inconsistent with these established purposes. Nevertheless, the HDMP delegates the responsibility of justifying the purposes for data collection, processing, and sharing to the executive, to be determined at a later point. This absence of clarity regarding the precise purposes for data sharing compromises transparency and accountability, posing a risk to privacy. Furthermore, it bestows excessive discretionary power upon the executive to potentially alter these purposes arbitrarily, without undergoing thorough scrutiny.

The National AIDS Control Program Data Management Guidelines, 2020[60] exhibit similar shortcomings to the HDMP. These guidelines lack precision regarding the categories of data that will be collected and shared, offering limited insight into purpose limitation and the duration of data retention.[61] Furthermore, they lack well-defined organizational and technological protocols to ensure the confidentiality of individuals' HIV status by relevant entities. Although they affirm that personally identifiable data will not be shared with third parties for research purposes, the guidelines do not specifically identify the types of non-personal data that can be shared. Additionally, they do not acknowledge that anonymization is no longer considered an entirely foolproof method for preserving privacy, given that recent research indicates that in the era of big data and data mining, anonymized datasets can be relatively easily de-anonymized.[62]

Although the HDMP proclaims that the utilization of Aadhaar for creating a Unique Health Identity (UHID) is voluntary, recent experiences with COVID-19 vaccination reveal a different reality. Not only did Aadhaar become de facto mandatory for access to vaccines, but those who provided their Aadhaar number for vaccination inadvertently ended up having a UHID generated and linked to it without their informed consent.[63] This situation mirrors the actions of various state governments that mandated the submission of Aadhaar for obtaining antiretroviral treatment for HIV.[64] This raised concerns about the potential disclosure of HIV status, as well as the disclosure of sexual orientation and drug use status for many individuals, leading to a significant number of people living with the virus avoiding healthcare facilities altogether.[65] When officials stated in the media that the use of Aadhaar was encouraged but not compulsory, it was evident that it was being strongly enforced at healthcare facilities, much like the experience during COVID-19 vaccination.[66] In the absence of comprehensive privacy legislation, individuals have limited

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[60] National AIDS Control Programme Data Management Guidelines (2020).

[61] *id.*

[62] Luc Rocher, L., Hendrickx, J.M. & de Montjoye, YA., *Estimating the success of re-identifications in incomplete datasets using generative models*, Nat Commun 10, 3069 (2019).

[63] Sarthak Dogra, *Took Covid Vaccine Using Aadhaar? Your National Health ID Has Been Created Without Your Permission*, INDIA TODAY, May 24, 2021.

[64] Aarti Dhir, *HIV Treatment to be Linked to Aadhaar*, THE HINDU Feb. 2, 2015.

[65] Shruti Tomar, *Linking Benefits for AIDS Patients to Aadhaar Triggers Privacy Concerns', Hindustan Times,* THE HINDUSTAN TIMES April 3, 2017.

[66] Menaka Rao, *Why Aadhaar Is Prompting HIV-Positive People to Drop Out of Treatment Programmes in India*, SCROLL (Nov. 17, 2017), https://scroll.in/pulse/857656/across-india-hiv-positive-people-drop-out-of-treatment-programmes-as-centres-insist-on-aadhaar

control over their data and limited avenues for recourse in the event of a breach, as they might not even be notified of such breaches.

The Indian government claims Aadhar details are required to track individuals who are lost and to follow up for improving treatment adherence. However, this leads to distrust in the system which eventually leads to people being driven away from accessing health.[67]

CONCLUSION

Efforts in the legislative and programmatic aspects of HIV underscore the critical need for precision and careful implementation when dealing with complex health challenges. Being imprecise and thoughtless in our actions can seriously hinder public health initiatives aimed at managing the disease. This can, unfortunately, lead to increased stigma in already vulnerable and marginalized communities, erode trust in the healthcare system, and drive people towards spurious remedies and risky behaviors.

Empowering individuals through informed consent, along with the provision of accurate information, plays a pivotal role in this context. Protecting individuals by ensuring non-discriminatory practices and safeguarding their confidentiality is crucial. These elements create an environment where individuals are more likely to make positive changes in their behavior and take responsibility for their actions. Together, these principles are fundamental in achieving a successful response to the challenges presented by HIV.

The importance of maintaining the confidentiality of a person's health status extends far beyond the context of HIV. In the digital age, ensuring such confidentiality has grown increasingly complex, with legal frameworks often struggling to keep pace with rapidly advancing technology. Policies like the HDMP and forthcoming data protection laws that pertain to health information should be crafted with the same level of precision and diligence found in laws and protocols related to HIV. It is the bare minimum owed to patients in upholding the sanctity of their confidentiality.

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