



**PRIVACY
INTERNATIONAL**

ENHANCING PRIVACY AND CONFIDENTIALITY IN THE MANAGEMENT OF PUBLIC HEALTH DATA

Advocacy for the inclusion of the privacy and data protection needs of PLHIV and Key Populations

A BRIEF

December 2020

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INTRODUCTION

Privacy rights are critical - for the protection of PLHIV and key populations' right to health

The right to health is closely related to and dependent upon the realization of other human rights, as contained in the International Bill of Rights, including the rights to food, housing, work, education, human dignity, life, non-discrimination, equality, the prohibition against torture, privacy, access to information, and the freedoms of association, assembly and movement. These and other rights and freedoms address integral components of the right to health.

UN Economic and Social Council, 2000, General Comment No. 14, *The right to the highest attainable standard of health (Article 12 of the International Covenant on Economic, Social and Cultural Rights)*

The right to privacy explained

The UN High Commissioner for Human Rights in her 2018 Annual Report noted that the right to privacy can be considered as the presumption that individuals should have an area of autonomous development, interaction and liberty, a “private sphere” with or without interaction with others, free from state intervention and from excessive unsolicited interaction by other uninvited individuals.¹

In Kenya, the Constitution, at Article 31 provides for the right to privacy which is also well articulated in international human rights law including pronouncements of UN Special Rapporteurs.² In the arena of public health, more so, in HIV prevention and treatment, the importance of privacy cannot be overemphasized. With the increasing frequency of valid concerns being raised about the privacy of medical records and personal information, there is need for the issue to be addressed in specific legislation, guidelines and practice.

Digital technologies for health service delivery:

The use of digital technologies has been argued to enable faster and large-scale delivery of health services including contact tracing, epidemiological surveillance and tracking of movements of specific populations for targeted health interventions. Many health service providers now use electronic health records including use of mobile phones for provision of health education. Communities of PLHIV and key populations and civil society organizations have over the years analysed the use of and introduction of digital technologies with a focus on how they affect privacy rights, their impact on socioeconomic rights, including questioning whether they are really necessary in-service delivery. Digital technologies, while transformative, they can serve as a double-edged sword that may either lead to collective human flourishing or collective demise³.

¹ UN Human Rights Council, 39th Session. 2018. “*The Right to Privacy in the Digital Age: Report of the UN High Commissioner for Human Rights*”

See also:

UN Human Rights Council, 13th Session. 2009. “*Report of the Special Rapporteur on the promotion and protection of human rights and fundamental freedoms while Countering terrorism, Martin Scheinin.*” Para 11

UN Human Rights Council, 23rd Session. 2013. “*Report of the Special Rapporteur on the promotion and protection of the right to freedom of opinion and expression, Frank la Rue.*” Para 22 & 42

² See UN General Assembly. 2019. “*Report of the Special Rapporteur on extreme poverty and human rights.*” A/74/48037 and;

UN General Assembly. 2019a. “*Report of the Special Rapporteur on promotion and protection of the right to freedom of opinion and expression.*” A/73/348 and;

UN Human Rights Council (UNHRC). 2019. “*Report of the Special Rapporteur on promotion and protection of the right to freedom of opinion and expression.*” A/HRC/41/35.

³ UN Human Rights Council (UN HRC), 2020 “*Panel discussion on the impacts, opportunities and challenges of new and emerging digital technologies with regard to the promotion and protection of Human Rights*” Statement by Nada Al- Nashif, UN Deputy High Commissioner for Human Rights. <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=26050&LangID=E>

The outbreak of COVID-19⁴ a contagious virus, currently with no particular treatment or vaccine, which pandemic has further highlighted a precarious system where privacy rights can and continue to be violated with public health as an excuse. For those most vulnerable including people living with HIV (PLHIV) and key populations⁵ this adds up to the existing vulnerabilities of the health and personal data being exposed and used in a way that is detrimental to their health and well-being. The pandemic has deepened and worsened discrimination and inequalities that existed before and it has also been used as an excuse for human rights violations by putting in place public health protocols that limit freedoms - sometimes being pushed beyond limit. There have been excesses like strengthening surveillance powers, threatening threats to privacy, exceeding what is required for public health, among others.⁶

Countries, including Kenya, have put in place various measures⁷ designed to protect the health of their populations, as well as to protect national health systems from being overwhelmed by COVID-19 cases. While digital technologies for health interventions like contact tracing apps, biometric registrations and epidemiological surveillance could bring forth opportunities for COVID-19 prevention, they could also be used to violate the right to health and other associated rights.

The problem - no legal safeguards and enforcement?

Kenya is quickly migrating to the use of technology and as a result, methods of data collection, analysis and storage are slowly evolving from analogue 'paper-based' systems to the use of biometrics and other bio data while there are no corresponding legal safeguards and where they remotely exist, there is poor or lack of implementation and enforcement. This poses a problem as Kenya, did not, for a long time have any data protection laws and all data collected was being administered in a legal lacuna open to data breaches without any remedies.

Among people who work on legal and human rights responses to public health and HIV, there has been a worrying trend where the government in some instances has collected or tries to collect personal data without putting in place proper data protection guidelines to safeguard the said data from breach and misuse. For instance, in November 2016 the Government of Kenya announced plans to roll out the use of biometrics to determine key population size estimates as part of an Integrated Bio-Behavioural Surveillance study (IBBS). This was rejected by key population groups in Kenya due to fears of function creep where there was a possibility of police gaining access to health data and using it for arbitrary arrest and detention.⁸ They further cited the lack of data protection laws and noted that voluntarily providing their data would expose their data to function creep (with data collected for health purposes potentially being used by police to target key populations for arrest and arbitrary detention) and the risk of data breaches that could expose already stigmatized populations publicly to their families and communities.

In early 2019, the same government announced the roll-out of a new National Integrated Identity Management System (NIIMS - Huduma Number) which system involved the synchronization of all personal data and linking the same to a unique identifier code. This was challenged in court and the court pronounced itself on issues among others, violations and/or threatened violations on the right to privacy and that the registration process should be voluntary and not tied to any public.⁹

⁴It originated in Wuhan and first reported as a pneumonia of unknown cause to the WHO Country Office in China on 31 December 2019 and was eventually identified as a novel coronavirus and declared a Public Health Emergency of International Concern by WHO under the International Health Regulations, 2005 on 30 January 2020.

⁵UNAIDS considers gay men and other men who have sex with men, sex workers, transgender people, people who inject drugs and prisoners and other incarcerated people as the five main key population groups that are particularly vulnerable to HIV and frequently lack adequate access to services. See <https://www.unaids.org/en/topic/key-populations>

⁶Lieberman, Amy. 2020, "COVID-19 is not an 'excuse' for human rights violations". DEVEX, 2 October

⁷Executive Order on Tax Laws - Legal Notice No. 35 (Amendment of Tax Rates), Safeguards against adverse economic impact of COVID-19, Legal Notices with regulations under the Public Health Act - Legal Notice No. 49 Public Health (Prevention, Control and Suppression of COVID-19) Rules, 2020 and Legal Notices 50-54 & 58 on Restriction of Movement of persons and Legal Notice No. 39 The Public Order (State Curfew) Order, 2020, among others. See <http://kenyalaw.org/kenyalawblog/kenyas-response-to-covid-19/>

See also, Ministry of Health, COVID-19 Protocols and Guidelines. <https://www.health.go.ke/#1585137302557-b337f64d-c55873d1-981a>

⁸See KELIN and the Key Populations Consortium.2018. "Everyone said no": Biometrics, HIV and human rights, A Kenya case study.

⁹See, Nubian Rights Forum & 2 others v Attorney General & 6 others; Child Welfare Society & 9 others (Interested Parties) [2020] eKLR

Further, in November 2020, the government announced a phased roll-out of the Huduma Cards (resulting from the NIIMS) from 1 December 2020 noting that the card will be the primary source of data for every citizen and foreigner therefore making it mandatory.¹⁰

Further, on 31 October 2020, the President launched the biometric registration of a million indigents into the Universal Health Coverage program - with the indigents termed as those who are extremely poor and vulnerable individuals who cannot afford to pay for medical care.¹¹ The President, during the launch urged Parliament to fast-track the necessary legislation to fully implement the program, therefore begging the question of whether the risks linked to the project, including collection of biometric data specifically of what they have termed as indigents, who almost always lack the power to negotiate about their human rights have been analysed.

Some of the measures put in place due to COVID-19, with developments in the pandemic, human rights advocates have argued that they have potential to violate rights of citizens including the privacy and confidentiality of PLHIV and key populations. There is fear, especially, among PLHIV and key populations that this exercise and the data collected may be used for other purposes - including the violation of rights and potentially exposing marginalized groups for blame around COVID-19 transmission.¹²

The Global Commission on HIV and Law in their 2018 Supplement also warns of the risk of digitally - collected health information being used by the polices and other parties and how new technologies present potential for misuse.¹³

Some of the risks associated with the use of digital technologies including biometrics in health and in particular the HIV response and public health emergencies may include:¹⁴

- i. Risk in access created by the digital divide, particularly for women and girls and key populations
- ii. Risks of weak national data protection and privacy laws, and weak enforcement of them by government and courts
- iii. The risk that employing digital identities may actually reduce access to health services, especially for marginalized groups who avoid using digital identities or giving biometric data out of fear of stigma, discrimination and arrest
- iv. The risk of privacy violations, especially for key populations and other marginalized groups, and women and girls
- v. The risk of surveillance and restrictions on freedom of expression for HIV, TB and key populations groups, well as groups advocating for sexual reproductive health and rights
- vi. The risk of function creep and targeting of individuals and groups based on their behaviour or ethnicity by malicious actors or hostile states.

¹⁰Wambui Mary. 2020. "Six-year old's to get IDs in Huduma plan". Nation, 20 September <https://nation.africa/kenya/news/six-year-olds-to-get-ids-in-huduma-plan-2303574?fbclid=IwAR23Vqm8qSbTu5vZvulibT9GWLqQsaaJID9nUcPCgEioLJtu3Innn65-WXO>

See also Mueni Jemimah. 2020. "Matiangi'i, Mucheru to roll out Huduma Namba Card distribution". Capital News, 18 November <https://www.capitalfm.co.ke/news/2020/11/matiangi-mucheru-to-roll-out-huduma-namba-card-distribution/>

¹¹Otieno, B.2020. 'Uhuru launches biometric Universal Health Coverage registration' The Star, 31 October 2020 <https://www.the-star.co.ke/news/2020-10-31-uhuru-launches-biometric-universal-health-coverage-registration/>

¹²See Davis, Sara L.M. 2020 Contact tracing apps: Extra risks for women and marginalized groups. Health and Human Rights Journal Blog.

¹³Global Commission on HIV and the Law. 2018. Risks, Rights and Health: Supplement. UNDP: New York. <https://hivlawcommission.org/supplement/>

¹⁴GSM. 2016. "Regulatory and Policy trends impacting Digital Identity and the role of mobile: Considerations for emerging markets". <https://www.gsma.com/mobilefordevelopment/wp-content/uploads/2016/10/Regulatory-and-policy-trends-impacting-Digital-Identity-and-the-role-of-mobile.pdf>

See also, Dixon P. (2017). A Failure to "Do No Harm" -- India's Aadhaar biometric ID program and its inability to protect privacy in relation to measures in Europe and the U.S. Health and technology, 7(4), 539–567. <https://doi.org/10.1007/s12553-017-0202-6>

THE RIGHT TO PRIVACY AND THE HIV RESPONSE



For people living with HIV and those at a higher risk of HIV infection - key populations, their right to health is dependent on other rights including the right to privacy. Human rights including the right to privacy, are inextricably linked with the spread and impact of HIV on individuals and communities around the world. A lack of respect for human rights fuels the spread and exacerbates the impact of the disease, while at the same time undermining the progress in the realization of human rights. This link is apparent in the disproportionate incidence and spread of the disease among certain groups, which, depending on the nature of the epidemic and the prevailing social, legal and economic conditions, include women, children, those living in poverty and key populations, among others.¹⁵ For instance, in July 2020, UNAIDS reported that the relative risk of key populations acquiring HIV infections compared to the rest of the population is high. Key populations, while they constitute small proportions of the general population, they are at an elevated risk of acquiring HIV infection, in part due to discrimination and social exclusion.¹⁶ To understand the relationship between HIV & AIDS and human rights and in particular, the right to privacy, see below three factors that explain that link:

Increased vulnerability:

Certain groups are more vulnerable to contracting the HIV virus because they are unable to realize their civil, political, economic, social and cultural rights. For example, individuals who are denied the right to freedom of association and access to information and right to privacy may be precluded from discussing issues related to HIV and taking other preventive measures to protect themselves from HIV infection.

Discrimination and stigma:

The rights of people living with HIV are often violated because of their presumed or known HIV status, causing them to suffer both the burden of the disease and the consequential loss of other rights. *Stigmatization and discrimination which usually comes as a result of breach of privacy confidentiality may obstruct their access to treatment and may affect their employment, housing and other rights.* This, in turn, contributes to the vulnerability of others to infection, since HIV-related stigma and discrimination discourages individuals infected with and affected by HIV from contacting health and social services. The result is that those most needing information, education and counselling will not benefit even where such services are available.

Impedes an effective response:

Strategies to address the epidemic are hampered in an environment where human rights are not respected. For example, discrimination against and stigmatization of key populations such as injecting drug users, sex workers, and men who have sex with men drives these communities underground. This inhibits the ability to reach these populations with prevention efforts, and thus increases their vulnerability to HIV. Likewise, the failure to provide access to education and information about HIV, or treatment, and care and support services further fuels the epidemic. These elements are essential components of an effective response to HIV, which is hampered if these rights are not respected.

The right to privacy and the right to personal data protection - which is derived from the right to privacy are both important in the HIV response especially when dealing with data associated with PLHIV and key populations.

¹⁵See, OHCHR & UNAIDS. 2006. *International Guidelines on HIV/AIDS and Human Rights*. Geneva

¹⁶UNAIDS. *Global AIDS update. 2020. Seizing the moment: Tackling entrenched inequalities to end epidemics.* https://www.unaids.org/sites/default/files/media_asset/2020_global-aids-report_executive-summary_en.pdf

SPOTLIGHT: RIGHTS OF PLHIV AND KEY POPULATIONS DURING PUBLIC HEALTH EMERGENCIES

The COVID-19 pandemic has brought to the fore the challenge of the right to privacy versus the right to right to the highest attainable standard of health which is an issue that has been faced by communities of PLHIV and key populations in the HIV response for a long time. UNAIDS notes that the presence of stigma specific to certain health conditions has been observed in the HIV epidemic, the outbreaks of the Ebola virus and Zika virus and now the COVID -19 pandemic. The anticipation of stigma during a pandemic can interfere with the adoption of preventive measures, timely testing and adherence to treatment. Many forms of stigma and discrimination have surfaced since the identification of COVID-19. In several countries, the UNAIDS notes that people living with HIV report being required to disclose their HIV status when seeking HIV services during lockdowns, especially adolescents, women and transgender people.¹⁷

Intrusive contract tracing mechanisms¹⁸ both digital and physical employed during this epidemic adds to the already fragile data collection, possible misuse and storage concerns already raised by PLHIV and communities of key populations in Kenya. While collection and sharing of biomedical data is necessary for the containment of infectious diseases, this pandemic has escalated the need to collect and share data in addition to tracking people's movements, it is further not clear what will happen to the data once the pandemic ends. The fear of misuse of data or breach of privacy is not unique to this pandemic.

People living with HIV and tuberculosis (TB) are significantly impacted by COVID-19. Modelling has estimated the potential catastrophic impacts of the COVID-19 pandemic, with increases of up to 10%, 20% and 36% projected deaths for HIV, TB and malaria patients, respectively, over the next five years. Key population groups and entire communities are facing extreme disruptions to their subsistence and livelihoods. Sex workers in most countries operate within the informal economy and are currently prevented from working and face destitution and hunger, together with their dependents. People who inject drugs often have no access to income and to prevention, treatment and rehabilitation services. Lesbian, gay, bisexual, transgender and intersex communities are facing further stigmatization, violence and alienation.

UNAIDS, 2020. UNAIDS calls on governments to strengthen HIV - sensitive social protection responses to the COVID-19 pandemic

For instance, in Kenya, the government gazetted the Public Health (Prevention, Control and Suppression of COVID-19) Regulations, 2020 where the government puts the responsibility on third parties to notify medical or public health officers of any suspected cases of COVID-19¹⁹ and the power of search is given to public health officers or health inspectors.²⁰ The foregoing provisions have the potential to be abused by those in authority and community members to target and a the detriment of PLHIV and key populations because of their known or perceived status. Further, violations in the healthcare sector that stem from such policy formulation and implementation gaps may include the disclosure of personal health information to third parties without consent; unlimited or unnecessary collection of personal health data; provision of personal health data given for research; and commercial uses without de-identification of data and improper security standards, storage and disposal which may result to some forms of discrimination and stigma. Such new regulations must come with attendant data protection policies and legislation to ensure privacy of data collected during health emergencies.

¹⁷UNAIDS 2020, Reference. Addressing stigma and discrimination in the COVID-19 response: Applying the evidence of what works from HIV related stigma and discrimination in six settings to the COVID -19 response.

¹⁸See Ministry of Health, 2020. "COVID-19 Outbreak in Kenya – Daily Situation report – 118". 13 July

¹⁹Regulation 2 of the Public Health (Prevention, Control and Suppression of COVID-19) Regulations, 2020

²⁰Regulation 5 of the Public Health (Prevention, Control and Suppression of COVID-19) Regulations, 2020



THE LEGAL FRAMEWORK: Will laws help?

The law alone cannot stop AIDS. Nor can the law alone be blamed when HIV responses are inadequate. But the legal environment can play a powerful role in the well-being of people living with HIV and those vulnerable to HIV. Good laws, fully resourced and rigorously enforced, can widen access to prevention and health care services, improve the quality of treatment, enhance social support for people affected by the epidemic, protect human rights that are vital to survival and save the public money.

The Global Commission on HIV and Law: Risks, Rights & Health, 2012

The Global Commission on HIV and Law in 2012 argued that while the law and its institutions can protect the dignity of all people living with HIV, and in doing so fortify those most vulnerable to HIV- like key populations, the law can also do grave harm to the bodies and spirits of people living with HIV by perpetrating discrimination and isolate the people most vulnerable to HIV from services that could help them cope with the virus.

The legal and policy framework has been categorized into five areas: Firstly, the Constitution of Kenya, 2010 as the supreme law of the republic and as such guides the formulation and implementation of all laws, policies, guidelines and regulations. Secondly, international and regional policy instruments, including model laws, by virtue of Article 2 (5) & (6) of the Constitution of Kenya form part of the Laws of Kenya. The most relevant of these instruments are those which entrench frameworks that promote and protect human rights. Thirdly, legislation enacted by Parliament of Kenya (i.e., the National Assembly and Senate) at the national level. Fourth, policies, regulations and guidelines formulated by the Executive while exercising its functions. Fifth, are judicial pronouncements and decisions that have been made which may have an impact on privacy rights in the HIV response and how public health emergencies are handled.

1. THE CONSTITUTION OF KENYA, 2010:

The Constitution of Kenya, 2010 as the supreme law of the republic, sets standards with which all laws, policies, and guidelines must conform.²¹ An important provision of the Constitution is the entrenchment of national values and principles of governance that State officers must adhere to in enacting or interpreting any law; making or implementing policies; and in application of the Constitution. These are outlined under Article 10 and include participation of the people, human dignity, equity, social justice, inclusiveness, equality, human rights, non-discrimination and protection of the marginalized, among others.²² The Constitution has an expansive Bill of Rights section which guarantees fundamental human rights and freedoms, and which can be relied on by all including PLHIV and key populations to advocate for their rights. In the bill of rights, social economic rights, including the right to the highest attainable standard of health, are guaranteed to Kenyans. The bill of rights has provisions that can be used to support and safeguard the rights of people living with HIV and key populations. Article 19(1) provides that the Bill of Rights is an integral part of Kenya's democratic state and is the framework for social, economic and cultural policies. The rights and fundamental freedoms in the Bill of Rights further belong to each individual and are not granted by the State.²³

The **right to health** is guaranteed at Article 43(1) providing for the “right to the highest attainable standard of health” which includes the “right to health care services, including reproductive health care.” In addition, the government has the obligation to observe, respect, protect, promote and fulfil the right.²⁴ For the right to health to be achieved, other rights like the **right to privacy**²⁵ must be protected and guaranteed including on the information relating to their family or private affairs unnecessarily required or revealed. The right to privacy is relevant in ensuring that information about a person's HIV and health status is kept confidential and is not released without their consent, obtained or disclosed under compulsion.

²¹See Article 2(1) and (4) Constitution of Kenya.

²²Other national values and principles of governance as outlined in Article 10 of the Constitution include patriotism, national unity, sharing and devolution of power, rule of law, democracy, human dignity, good governance, integrity, transparency and accountability and sustainable development.

²³Article 19(3)(a).

²⁴Article 21(1), Constitution of Kenya

²⁵Article 31, Constitution of Kenya

2. INTERNATIONAL AND REGIONAL FRAMEWORKS:

By virtue of Article 2(5) & (6) of the Constitution, ratified international treaties and conventions are recognized as part of the laws of Kenya. The article also recognizes the general rules of international law as being applicable to Kenya.

The **Universal Declaration of Human Rights (UDHR)** provides that no one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.²⁶

The right to privacy is provided for under Article 17 of the **International Covenant on Civil and Political Rights (ICCPR)** is relevant to the protection of persons living with and affected by HIV and key populations from unauthorized use or publication of their HIV or health-related information. The **International Guidelines on HIV/AIDS and Human Rights**²⁷ on the other hand, have interpreted this right in the context of HIV as follows: “The right to privacy encompasses obligations to respect physical privacy, including the obligation to seek informed consent to HIV testing and privacy of information, including the need to respect confidentiality of all information relating to a person’s HIV status.”

These guidelines were developed by United Nations Programme on HIV/AIDS (UNAIDS) and United Nations High Commissioner for Human Rights (OHCHR) to provide guidance to states on how to take efficacious steps in order to guarantee human rights in the context of HIV/AIDS.²⁸ The Guidelines advance that States should ensure that their public health laws adequately address public health issues raised by HIV, that their provisions applicable to casually transmitted diseases are not inappropriately applied to HIV and that they are consistent with international human rights obligations. This means that the law must guarantee that reported HIV and AIDS cases must be subjected to stringent rules of confidentiality and data protection. The Guidelines also obligate States to legislate protective laws that protect persons living with HIV in order to guarantee their privacy, confidentiality and ethics involving human subjects. Personal HIV data or related information must be incorporated within the meanings of personal medical data that is subject to protection, it should also forbid any unsanctioned use and or even publication of personal HIV data.

The **Convention on the rights of the Child**²⁹ provides that no child should be subjected to arbitrary or unlawful interference with their privacy and that they have the right to protection against such interference or attacks.

The **Convention on the rights of persons with disabilities**³⁰ also makes provisions on the right to privacy noting that persons with disabilities shall not be subjected to arbitrary interference with their privacy and that state parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.

The World Health Organization, drawing its mandate from Articles 21 (a) and 22 of its Constitution adopted the **International Health Regulations, 2005**³¹ designed to prevent international spread of disease as has been witnessed since the beginning of 2020. The purpose and scope of the IHR, 2005 is to “**prevent, protect against, control and provide a public health response to the international spread of disease in ways that are commensurate with and restricted to public health risks** and which avoid unnecessary interference with international traffic and trade.” Article 3 of the IHR, 2005 provides that while implementing the IHR, countries must respect the dignity, human rights and fundamental freedoms of persons. They should be further guided by the Charter of the United Nations and Constitution of the WHO. For states, while legislating and implementing such legislation, they should uphold the purpose of the IHR, 2005. Article 45 of the IHR 2005, while addressing the treatment of personal data during

²⁶Article 12 of the Universal Declaration of Human Rights

²⁷Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS, *International Guidelines on HIV/AIDS and Human Rights 2006 Consolidated Version*, 2006.

²⁸*International Guidelines on HIV/AIDS and Human Rights*

²⁹Article 16 of the Convention of the Rights of the Child, 1989

³⁰Article 22 of the Convention on the Rights of Persons with Disabilities, 2007

³¹See, WHO, *International Health Regulations, 2005*. <https://www.who.int/publications/i/item/9789241580496>

public health emergencies of international concern, provides that while states may disclose and process personal data where essential for purposes of assessing and managing a public health risk, they must ensure that personal data are:

- i. processed fairly and lawfully and not further processed in a way incompatible with that purpose.
- ii. adequate, relevant and not excessive in relation to that purpose.
- iii. accurate and, where necessary, kept up to date; every reasonable step must be taken to ensure that data which are accurate, or incomplete are erased or rectified; and
- iv. not kept longer than necessary.

General Assembly resolutions and General Comments:

In addition, the UN General Assembly has made resolutions on the right to privacy as discussed below:

- i. On the principle of legality, they note that any interference on the right to privacy must not be arbitrary or unlawful, bearing in mind what is reasonable with regard to the pursuance of legitimate aims, and recalling that States that are parties to the International Covenant on Civil and Political Rights must take the necessary steps to adopt laws or other measures as may be necessary to give effect to the rights recognized in the ICCPR.³²
- ii. On retention of data, they noted the increase in the collection of sensitive biometric information from individuals and stressed that States must respect human rights obligations when collecting, processing, sharing and storing biometric information by, inter alia, considering the adoption of data protection policies and safeguards.³³
- iii. On distinctions metadata and general content, they noted that, while metadata may provide benefits, certain types of metadata, when aggregated, can reveal personal information that can be no less sensitive than the actual content of communications and can give an insight into an individual's behaviour, social relationships, private preferences and identity.³⁴
- iv. On adequate safeguards, effective measures have to be taken by States to ensure that information concerning a person's private life does not reach the hands of persons who are not authorized by law to receive, process and use it, and that such information is never used for purposes incompatible with the ICCPR.³⁵
- v. Committee on the Rights of the Child in General Comment No. 3 of 2003 - HIV/AIDS and the rights of the child noted that state parties must protect the confidentiality of HIV test results consistent with the obligation to protect the right to privacy of children, including within health and social welfare settings and information on the HIV status of children may not be disclosed to third parties including parents without consent.³⁶

Due to technological advancement and therefore the evolving nature of the human rights framework, UN Special Rapporteurs have contributed to the debate on privacy at the UN level. The former UN Special Rapporteurs on Extreme poverty and human rights and Right to freedom of opinion and expression identified sets of issues of importance in relation to privacy. In October 2019, Philip Alston, in his report to the UN General Assembly, considered the impact of digital tools and artificial intelligence on economic and social rights noting that with the increase in automation, prediction, surveillance and other functions the result is often a reduction in economic and social rights.³⁷ He noted,

Often.....the digitization of welfare systems has been accompanied by deep reductions in the overall welfare budget, a narrowing of the beneficiary pool, the elimination of some services, the introduction of demanding and intrusive forms of conditionality, the pursuit of behavioural modification goals, the imposition of stronger sanctions regimes and a complete reversal of the traditional notion that the state should be accountable to the individual.

³²U.N. General Assembly Resolution on the Right to Privacy in the Digital Age, U.N. Doc. A/RES/73/179 (17 December 2018)

³³U.N. General Assembly Resolution on The Right to Privacy in the Digital Age, U.N. Doc. A/RES/73/179 (17 December 2018)

³⁴U.N. General Assembly Resolution on the Right to Privacy in the Digital Age, U.N. Doc. A/RES/73/179 (17 December 2018)

³⁵U.N. Human Rights Committee - CCPR, General Comment No. 16: Article 17 (Right to Privacy), U.N. Doc. HRI/GEN/1/Rev.1 at 21 (8 April 1988)

³⁶Committee on the Rights of the Child, General Comment No. 3, HIV/AIDS and the rights of the Child, U.N. Doc. CRC/GC/2003/1 (2003)

³⁷UN General Assembly 2019. "Report of the Special Rapporteur on extreme poverty and human rights", A/74/48037.

The OHCHR provides advice on when rights can be limited, this is also applicable to privacy rights, and must be done under specified law. Such limitations can only be justified if they meet the following standards:³⁸

- i. **Provided by law:** any restriction must have a formal basis in law, which is accessible and formulated with sufficient precision to enable individuals to foresee whether a particular action is in breach of the law and to assess the likely consequences of any breach.
- ii. **In pursuit of a legitimate aim:** any restriction must be shown by the state to have the genuine purpose and demonstrable effect of protecting a legitimate aim recognized under international law.
- iii. **Necessary and proportionate in pursuance of a legitimate aim:** any restriction is necessary and proportionate in a democratic society if it is the least restrictive means available for protecting that interest.

At the East African level, the **East African Community (EAC) HIV and AIDS Prevention and Management Act (2012)** passed by the East African Legislative Assembly (EALA) in 2012 and ratified by Heads of States of the five EAC Countries (Kenya, Uganda, Burundi, Tanzania, and Rwanda). The Act makes provision for the prevention and management of HIV and AIDS and for the protection and promotion of human rights of persons living with or affected by HIV and AIDS in the EAC. It has provisions on the protection of the rights of persons living with or affected by HIV including the right to privacy and confidentiality, protection from discrimination³⁹ and the protection of vulnerable and most at-risk populations - including children, women and girls, youth and adolescents, persons with disability, prisoners, and other vulnerable people. The Act requires that for populations identified as being most at risk, services must be provided in a non-discriminatory manner and they must also access to quality health care services.⁴⁰

3. NATIONAL LAWS

The Health Act, 2017:

The Health Act⁴¹ was enacted in 2017 to establish a unified health system; coordinate the inter-relationship between the national government and county government health systems; and provide for regulation of health care service and health care service providers, health products and health technologies.⁴² Under section 3, the Act seeks to protect, respect, promote and fulfil the **health rights** of all persons in Kenya to the progressive realization of their right to the highest attainable standard of health, including reproductive health care and the right to emergency medical treatment. It also seeks to protect, respect, promote and fulfil the rights of children to basic nutrition and health care services contemplated in Articles 43(1) (c) and 53(1) (c) of the Constitution. Third, the Act seeks to **protect, respect, promote and fulfil the rights of vulnerable groups** as defined in Article 21⁴³ of the Constitution in all matters regarding health. This underscores the fact that the Act embraces the need to ensure realization of rights.

The Act unbundles the responsibility of the State to ensure the right to health is realized. In this regard, the States duty to observe, respect, protect, promote and fulfil the right to health is defined in the Act to entail:

- iv. developing necessary policies, laws and other necessary measures.
- v. ensuring the prioritization and adequate investment in research.
- vi. ensuring the realization of the health-related rights and interests of vulnerable groups within society.
- vii. ensuring the provision of a health service package at all levels of the health care system, which shall include services addressing the promotion, prevention, curative, palliative and rehabilitation, as well as physical and financial access to health care.

³⁸See UN Human Rights Office of the High Commissioner (UN OHCHR) & Inter-Parliamentary Union. 2016. "Human Rights - Handbook for Parliamentarians No. 26. <https://www.ohchr.org/documents/publications/handbookparliamentarians.pdf>

³⁹Section 25 of the EAC HIV and AIDS Prevention and Management Act

⁴⁰Sections 33-39 of the EAC HIV and AIDS Prevention and Management Act

⁴¹Act No 21 of 2017 Laws of Kenya.

⁴²See Preamble, Health Act 2017.

⁴³Article 21 of the Constitution defines the vulnerable groups to include women, older members of society, persons with disabilities, children, youth, members of minority or marginalized communities, and members of particular ethnic, religious or cultural communities.

The Act also provides for the right to reproductive health,⁴⁴ right to emergency medical treatment,⁴⁵ right to health information,⁴⁶ right to informed consent,⁴⁷ and **right to confidentiality**.⁴⁸ These empower people living with and affected with HIV to claim their reproductive rights, obtain health information, enjoy confidentiality and ensure that their right to informed consent is protected.

The Data Protection Act No. 24 of 2019

This Act of Parliament gives effect to Article 31 (c) and (d) of the Constitution, it establishes the Office of the Data Protection Commissioners, makes provision for the regulation of the processing of personal data, provides for the rights of data subjects and obligations of data controllers and processors. The act provides interpretation and defines some key terms that are important in ensuring privacy rights of PLHIV and key populations are upheld. Some of the terms include anonymization – the removal of personal identities from personal data, biometric data, consent, health data, processing data, sensitive personal data, third party among others.

The objective and purpose of the act is, a) to regulate the processing of personal data, b) to ensure that the processing of personal data of a data subject is guided by the principles set out in Section 25, c) to protect the privacy of individuals d) to establish the legal and institutional mechanism to protect personal data, and e) to provide data subjects with rights and remedies to protect their personal data from processing that is not in accordance with the act.

The act takes into account some of the main principles of data protection as described below:

- i. Lawfulness, fairness and transparency: section 25 (b) provides for the principles of data protection including that the processing must be lawful, fair and transparent to the data subject.
- ii. Purpose limitation: under Section 25 (d) any data processed must be for the legitimate purposes specified explicitly to the data subject when its collected.
- iii. Data minimization: under Section 25 (c) data should be collected for explicit, specified and legitimate purposes.
- iv. Accuracy: Section 25 (f) all data must be kept accurate and up to date and any inaccurate data should be erased or rectified.
- v. Storage limitation: personal identifying data may only be stored as long as necessary and for a specific purpose, otherwise it should be erased.
- vi. Integrity and confidentiality: Section 25 (a) provides that all data must be processed in accordance with the right to privacy of the data subject.
- vii. Accountability: the establishment of the Office of the Data Protection Commissioner to ensure enforcement of the act, offer oversight on data processing operations, promote self-regulation among data controllers and processors, enforcement and to receive and investigate complaints on infringement of rights prescribed in the act.

This act further makes provisions on rights of a data subject and how to exercise those rights - sections 26 & 27; collection of personal data - section 28; duty of data controller or processor to notify the data subject of rights, purpose of data, 3rd parties who data will be shared with and data security - section 29; lawful processing of personal data - section 30; need for data protection impact assessment - section 31; conditions of consent - section 32; processing of personal data of a child - section 33; processing of data - section 34; commercial use of data - section 37; notification and communication in case of data breach - section 43.

Section 46 specifically makes a provision on personal data relating to health - such data can only be processed by or under the responsibility of a health care provider or by a person subject to the obligation of professional secrecy under any law.

On public interest, section 46 (2) provides that personal health data can be processed if one of the reasons is that the processing is necessary for reasons of public interest in the area of public health. On national security on the other hand, personal data is exempt from the provisions of the Data Protection Act, 2019 if such data is necessary for national security as provided under Section 51 (2) (b). The lack of clear definitions of public interest and national security makes it possible for sections 46 (2) and 51 (2) (b) for abuse and could result to cases of stigma and discrimination of PLHIV and key populations.

⁴⁴Section 6.

⁴⁵Section 7.

⁴⁶Section 8.

⁴⁷Section 9.

⁴⁸Section 11.

The HIV and AIDS Prevention and Control Act, 2006:

The HIV and AIDS Prevention and Control Act No 14 of 2006 ensures the rights of people living with HIV and those affected by HIV are protected. The legislation provides for measures for the prevention, management and control of HIV and AIDS; protection and promotion of public health and for the appropriate treatment, and counselling, support and care of persons living with or affected by HIV or at risk of HIV.

The Act makes provisions for the following, among others:

- i. *HIV and AIDS education and information*, where the government is required to promote public awareness about the causes, modes of transmission, consequences, means of prevention and control of HIV and AIDS through a comprehensive nationwide educational and information campaign.⁴⁹
- ii. *Prohibition against compulsory testing*, where the Act prohibits and makes it an offence to compel another person to undergo an HIV test. Further, the Act prohibits compulsion to undergo an HIV test as a precondition (or for the continued enjoyment of) employment; marriage; admission to school; entry or travel out of the country; provision of health care, insurance cover or any other services.⁵⁰
- iii. *Provision for informed consent prior to HIV testing* as provided for under section 14 of the Act.
- iv. *Pre-test and post-test counselling*, where every testing centre is required to provide pre-test and post-test counselling to a person undergoing an HIV test and any other person likely to be affected by the results of the test.⁵¹
- v. *Provision for protection of HIV test results* as provided for under section 18 of the Act.
- vi. *Provisions for privacy and confidentiality* as provided for under sections 20 - 23 of the Act.
- vii. The Act further *establishes the HIV and AIDS Tribunal* with jurisdiction (excluding criminal jurisdiction) to hear and determine complaints arising out of any breach of the Act.
- viii. *Provisions prohibiting discriminatory practices* at the workplace, school, insurance, travel, burial, health institutions, and others.⁵²
- ix. *Provisions regulating HIV-related research* as provided for under sections 39 – 42 of the Act.

This act further makes provisions on rights of a data subject and how to exercise those rights - sections 26 & 27; collection of personal data - section 28; duty of data controller or processor to notify the data subject of rights, purpose of data, 3rd parties who data will be shared with and data security - section 29; lawful processing of personal data - section 30; need for data protection impact assessment - section 31; conditions of consent - section 32; processing of personal data of a child - section 33; processing of data - section 34; commercial use of data - section 37; notification and communication in case of data breach - section 43.

The Health Records and Information Managers Act, No. 15 of 2016

This is an Act of Parliament making provisions for the:

- i. Training, registration and licencing of the health records and information managers
- ii. Regulation of their practice
- iii. Provide for the establishment, powers and functions of the Health Records and information Managers Board.

This is particularly important as it makes provisions for the personnel who ensure management of health data at the facility level.

⁴⁹Part II of the Act (Sections 4-8).

⁵⁰See section 13 of the Act.

⁵¹Section 17.

⁵²Sections 31 -38

4. GUIDELINES, REGULATIONS AND STANDARD OPERATING PROCEDURES:

The Kenya HIV Testing Services Guidelines (2015)

These guidelines⁵³ provide for confidentiality in the context of HIV testing and counselling and obligating the service provider to hold in confidence medical or personal information regarding their clients. It provides that the names of clients can be used to facilitate referral and to aid in diagnosis and treatment. The guidelines provide that all HIV testing and counselling service delivery points should ensure that the policies, training and infrastructure needed to uphold client confidentiality and privacy are in place and adhered to.

Standard operating procedures in handling of health records and information management during the COVID-19 pandemic (2020)

It provides for the protection of information gathered in association with the care of the patient. It notes that the privacy of a patient encompasses several aspects including personal space (physical privacy), personal data (information privacy), personal choices including cultural and religious affiliations (decisional privacy) and personal relationships with family members and other intimates (associated privacy). Any health records and patient's information should be kept under strict confidence at all times.

The Draft HIV and AIDS Prevention and Control (Privacy) Regulations (2019)

These draft regulations apply to any person **processing HIV data** which relates to the prevention, management and control of HIV and AIDS. The draft regulations are meant to promote the right to privacy of an individual in relation to HIV data as envisaged under Article 31 of the Constitution; enhance confidentiality in the process of undertaking HIV tests and related medical assessments; provide standard guidelines on processing HIV data; enhance security of data, records or forms used in respect of processing of HIV data; protect HIV related information from unauthorized disclosure, access or transfer; and ensure that processing of HIV data is based on ethical principles and safeguards. The foregoing is also expected to enhance confidentiality and provide a clear guidance on how HIV data shall be collected, processed and stored while simultaneously adhering to data protection principles.⁵⁴

Data collection - this is can be found under *Part II* of the draft Privacy Regulations 2019. This part begins by establishing the rights as well as the duties of a data subject whom it defines as, "*an identified or identifiable natural person who is the subject of HIV data.*" Under the draft regulations, the rights of a data subject include but are not limited to the right to be informed the reasons, risks advantages as well as the manner in which data is processed, the right to privacy and confidentiality with regards to the analysis of their data, the right to consent or even withhold their consent during the collection and processing of their data, the right to access their data, the right to correction or erasure of false or misleading info in their data, the right to receive requests to transfer their data and the right to offer or refuse any such requests among others.

The draft regulations obligate a data controller not to collect any HIV information unless with the data subject's **informed consent**.⁵⁵ The data subject should be informed the reasons of collection unless such data is collected by a medical practitioner for the data subject's medical attention.⁵⁶ Data collected for research purposes must only be collected upon obtaining the requisite approvals from the relevant authorities not forgetting the data subject's informed consent where necessary. Additionally, the draft regulations guidelines recognize that there are individuals in the society incapable of giving informed consent and allows individuals mandated either by the data subject, the law or a court order as capable of giving informed consent on behalf of the data subjects.⁵⁷

Data processing - the very nature of an individual's HIV data is very sensitive and the same falls within the meaning of personal health data. The draft regulations do not specifically ascertain who can process personal HIV data but infer a data controller to be the one to process HIV data. The said regulations define a HIV data controller as a medical practitioner or any other person who processes HIV data.

⁵³NASCOP (2015) *The Kenya HIV Testing and Services Guidelines*

⁵⁴*The HIV and AIDS Prevention and Control (Privacy) Regulations, 2019*

⁵⁵*The fundamental aspects of informed consent shall be voluntary, specific, informed and unambiguous; may be given orally or through a written statement including by electronic means; given for each processing activity and ensure that the data subject is informed of the implication of his decision on consent.*

⁵⁶Regulation 7 of the *HIV and AIDS Prevention and Control (Privacy) Regulations, 2019*

⁵⁷Regulation 8

The draft regulations advance that a HIV data controller shall process HIV data fairly and considering the legitimate reason pursued; and that at all stages of the processing the data processor shall guarantee a fair sense of balance between all data subject's interests.⁵⁸ A healthcare practitioner is also expected to process HIV data in accordance with the norms, practices or prescribed guidelines and standards within the health sector.

The draft regulations also provide that a data subject has the right to obtain or access any of his or her personal HIV data that is held by a HIV data controller as per the provisions of the Access to Information Act.⁵⁹

Storage of HIV data - the draft regulations provide that a HIV data controller shall not only store HIV data in a way that guarantees the privacy of such data but also as per the best practices for safeguarding protected data.⁶⁰ The draft regulations further prohibit a HIV data controller from disclosing HIV data to 3rd parties,⁶¹ however, there are exceptions to the said provision which include when; the disclosure is made during communications with health care professionals involved in the treatment or care of the data subject, there has been accidental direct contact with the blood or bodily fluids of an individual which is of a nature that may transmit HIV, in the opinion of a healthcare professional, and a data subject gives informed consent permitting disclosure to that specific third party among others.

Both the draft Privacy Regulations of 2019⁶² and the Data Protection Act⁶³ advance that every data controller shall device proper, practical and administrative processes intended to incorporate crucial safety measures for handling personal data and to implement data protection principles in an effective way.

⁵⁸Guideline 12 of the HIV and AIDS Prevention and Control (Privacy) Regulations, 2019

⁵⁹Regulation 16 of the HIV and AIDS Prevention and Control (Privacy) Regulations, 2019

⁶⁰Regulation 17

⁶¹Regulation 18

⁶²Regulation 19

⁶³Section 41 of the Data Protection Act

5.0 JUDICIAL DECISIONS

Judicial decisions that have been made which have an impact on HIV and specifically that touch on the right to privacy are discussed.

a) **KELIN and 3 others v Cabinet Secretary Ministry of Health and 4 others [2016] eKLR - Petition 250 of 2015**

In 2016 the High Court made a decision protecting the right to privacy of persons living with HIV. This was in the case of [KELIN and 3 others v Cabinet Secretary Ministry of Health and 4 others \[2016\] eKLR - Petition 250 of 2015](#).⁶⁴ In that case, KELIN challenged in court a directive issued by the President on 23 February 2015 to County Commissioners, to work with County Directors of Education and Medical Services, to collect up-to-date data and prepare a report on: all school going children who are HIV positive and information on their guardians; the number of expectant mothers who are HIV positive; and the number of breastfeeding mothers who are HIV positive. This data was to be collected in a prescribed matrix that would directly link the above-mentioned persons with their HIV status, thus putting them at a risk of stigma and discrimination. The Court declared the presidential directive unconstitutional since the implementation of the directive violated the rights to privacy and the best interests of the child. The government was ordered to; within 45 days codify the names collected as a result of the directive and the same be stored in a manner that does not link the names of persons with their HIV status in a public document. This judgement is important as it upholds the right to privacy and confidentiality of PLHIV.

b) **A M v Spin Knit Limited [2013] eKLR**

The Court determined the case in favour of a claimant who had been forced to undergo an HIV test. The claimant's right to privacy and freedom from discrimination had also been infringed. The claimant was awarded **Kshs. 500,000/- in damages**.

c) **C.N.M v The Karen Hospital Limited Case No. HAT 008 of 2015**

The claimant had visited the respondent hospital to seek treatment for severe diarrhoea. The claimant was however subjected to a HIV test without her informed consent which test indicated that she was HIV positive. The claimant later learnt that information of her HIV status had been shared with her insurance company without her consent. In determining the case, the Tribunal held that the claimant had been compelled to undergo HIV testing without her informed consent contrary to sections 13 and 14 of HIV and AIDS Prevention and Control Act. The claimant was thus awarded Kshs. 1,000,000/- in damages. Further, the Tribunal held that by forwarding her invoice and bill with information on her diagnosis and treatment to her medical insurer violated section 22 of HIV and AIDS Prevention and Control Act since it was possible to infer the Claimant's HIV Status from the documents. The Tribunal awarded the claimant damages of Kshs. 1,500,000/- for the violation of her right to privacy and confidentiality.

d) **GSN v The Nairobi Hospital and 2 Others [2020] eKLR - Petition 24 of 2019**

The Petitioner sought declarations a) that the disclosure of their HIV status by the Nairobi Hospital to Liberty Assurance (KE) Limited without their consent was a violation of their right to privacy, b) that the disclosure of their HIV status by Liberty Assurance (KE) Limited to their employer without their knowledge and consent was a violation of their privacy, c) an order for general and exemplary damages for physical and psychological suffering occasioned by the violations. The court agreed with the petitioner and entered judgment in their favour and was awarded general damages to the tune of approximately USD 20,000.

e) **Nubian Rights Forum & 2 others v Attorney General & 6 others; Child Welfare Society & 9 others (Interested Parties) [2020] eKLR**

The Petitioners aggrieved by certain amendments made to the Registration of Persons Act, (Cap 107 Laws of Kenya) where the amendments established a National Integrated Management System (NIIMS) - a single source of personal information for all Kenyans and foreigners resident in Kenya. The 1st Petitioner raised the fact that there is no law in force to guarantee the privacy provisions provided for in the Constitution given the invasive process proposed to be implemented through NIIMS. The requirement under NIIMS for Global Positioning Systems Coordinates (GPS) and Deoxyribonucleic Acid (DNA) among other biometrics target individuals' communications and their exact whereabouts, which is very intrusive into one's right to privacy. They also argued that there was insufficient safeguards in the existing laws to protect the personal data collected.

⁶⁴See case at <http://kenyalaw.org/caselaw/cases/view/132167/>; See court documents for the case at <http://www.kelinkkenya.org/uhuru-hiv-list-declared-unconstitutional/>

The court found that the collection of DNA and GPS coordinates for purposes of identification is intrusive and unnecessary and to the extent that it is not authorised and specifically anchored in empowering legislation, it is unconstitutional and a violation of Article 31 of the Constitution. In terms of legislation, at the time of judgement, the court took judicial notice of the enactment of the Data Protection Act, 2019 and found that there is need for effective implementation of the act through an implementation framework which includes the appointment of the Data Commission, registration of data controllers and processors as well as enactment of operational regulations.



WHAT WAY FORWARD: How can we be better than before?

The provisions of the Constitution on the right to privacy, the enactment of the Data Protection Act, and the existing Health Records and Information Managers Act, HIV & AIDS Prevention and Control Act and other enabling legislation are a good starting point to ensure the protection and promotion of privacy rights of PLHIV and key populations. However, much more must be done to ensure implementation and enforcement of the existing laws while amending where necessary to provide further safeguards. Some of the lessons from the HIV response and now the pandemic caused by COVID-19 can help shape the actualization of privacy rights for PLHIV and key populations in future through the legal framework and its implementation. The following actions are therefore made:

Institution Specific Recommendations:

a) Recommendations to National Government (Executive)

- i. Review and consolidate policies relating to privacy and confidentiality, especially in HIV management and general health data of PLHIV and key populations, including to indicate how data will be collected and protected in line with human rights standards.
- ii. **Ensure effective application of laws in health service provision that guarantee the right to privacy.**
- iii. Ensure that all emergency measures, including curfews, restrictions on movement are legal, proportionate, necessary and non-discriminatory and do not put PLHIV and key populations in a situation where they are forced or coerced to disclose their personal and health and HIV information therefore increasing their risk of stigmatization.

b) Recommendations to County Governments (Executive)

- i. Ensure that HIV and health service delivery and the standards therein, are in line with the provisions of the law on privacy rights.
- ii. Provide continuous training of health care workers on the right to privacy and the legal provisions thereto.
- iii. Invest in infrastructure in health facilities to ensure confidentiality and timely services.
- iv. Take steps to prevent abuse, discrimination and breaches in confidentiality of PLHIV and key populations in health facilities including by:
- v. Facilitate human rights trainings on human rights-based approaches to service delivery including those involved in implementing the IHR, 2005 during public health emergencies should have a clear understanding of, and sustain the rights, obligations and procedures laid out in the regulations.

c) Recommendations for Parliament (National Assembly, Senate, County Assemblies)

- i. The National Assembly, Senate and County Assemblies should review, amend existing laws and enact new laws to ensure compliance with the provisions of the International Health Regulations, 2005 in order to sustain rights, obligations and procedures especially those in relation to the right to privacy.
- ii. Parliament should ensure that there are legal and policy safeguards in place where new technologies are used for surveillance in response to public health emergencies such as COVID-19.
- iii. The National Assembly Committee on Health should review all the relevant legislation on Privacy to ensure there is no conflict in provisions and functions to ensure privacy of health and HIV data.
- iv. Parliament should ensure transparent and meaningful public participation especially by communities of people living with HIV and key populations in law making processes.

d) Recommendations for Development Partners (Donors and UN Agencies)

- i. There is need to consult communities of PLHIV and key populations on new programs they are funding or partnering in with the Government of Kenya.
- ii. Ensure that any funding provided for health services focus on human rights including the right to privacy.

e) Recommendations to Civil Society Organisations (Including communities of PLHIV and key populations and the Private Sector)

- i. Provide legal empowerment on privacy rights and human rights in general to both rights holders and duty bearers.
- ii. Work with communities and other rights holders to spearhead social accountability on privacy rights in health service delivery.
- iii. Empower communities of PLHIV and key populations on the provisions of the law and human rights regarding the right to privacy including where to seek redress when rights are violated.

f) Recommendations to Media

- i. Develop media communication strategies that don't violate the right to privacy while reporting on health issues.
- ii. Use their platform for communication and advocacy on the right to privacy.

g) Recommendations to National Human Rights Institutions and other institutions created by relevant Acts of Parliament

These includes the Commission on Administrative Justice, Kenya National Commission on Human Rights and the National Gender and Equality Commission on the one hand and the Health Records and Information Managers Board and Office of the Data Protection Commissioner.

- i. Increase commissioners' and secretariats' capacities to provide support (investigative and advisory) services for health and HIV privacy rights violations.
- ii. Work with communities of PLHIV and key populations and CSOs to ensure access to information on privacy related issues including documents relating to service delivery.

h) Recommendations to Law Enforcement Agencies (including the Prison Service and Police)

- i. Develop protocols that outline Standard Operating Procedures addressing collection, processing and stor-age of personal and health data of PLHIV and key populations.
- ii. Conduct in-service trainings to ensure understanding, approaches, solutions and learning on data protection and privacy rights.
- iii. Strengthen the existing legal mechanisms for affected people - especially key populations to report cases of violation of privacy rights committed by state actors including law enforcement agencies.

i) Recommendations to the Judiciary

- i. Ensure judicial officers are adequately trained on the law and human rights relating to data protection and privacy rights, including at magistrate's court level.
- ii. Ensure through judicial pronouncements (and for the Chief Justice through their supervisory role) that courts are enforcing constitutional rights to privacy.

Issue Specific Recommendations:

j) Consent

- i. Review existing age of consent laws to ensure that they are in line with international and regional guidelines.
- ii. Provide guidance in form of Standard Operating Procedure on procurement of informed consent in health service delivery settings.

k) Education and Empowerment Consent

- i. Strengthen privacy rights in health care settings campaigns amongst communities, service providers (e.g., health care workers and justice actors) and law enforcement officials, to reduce instances of breach of privacy rights.
- ii. Train all those collecting, using and storing data on ethical practices – this would ensure better practices and promote and protect privacy rights.

l) Access to information

- i. Ensure that all patients (including people living with HIV and people with TB) have access to information on their diagnosis, treatment and medication.
- ii. Build the capacities of health care workers to enable them provide information on diagnosis, treatment and medication to patients and procurement of informed consent.

m) Transparency and accountability

- i. The office of the Data Commissioner must ensure that all data collected is used for the purpose it was collected.



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