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DIGITAL HEALTH RIGHTS: INITIAL ANALYSIS

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1 | INTRODUCTION

Digital health is growing rapidly; 2020 alone saw over $14.1 billion in new investment (Rock Health 2020). But as health systems increasingly become digitized, will access to health services be improved, or will digitization amplify inequalities, causing unintended harm to those who have historically experienced discrimination?

"Digital health" is a term used to cover diverse information and communication technologies used in health systems, from mobile applications, to health management information systems, to telemedicine and more. These technologies have the power to be transformative for health in low and middle-income countries. To make them work for everyone, though, requires thinking through the specific ways in which multiple existing forms of inequality may shape access and the interventions themselves, as well as how inequalities may shape the rights to privacy, autonomy, accountability, and participation for women and marginalized groups.

1.1 Background on the Digital Health and Rights Project

This project was developed by the Digital Health and Rights Advisory Group (DRAG), a consortium of social science researchers and civil society networks engaged in national and global health governance. We have gathered as individuals and organizations, working in academia, law, international organizations, and civil society to create a shared platform for collaboration to develop answers to the following questions:

- Will the local, national, and global governance of digital technologies and artificial intelligence (AI) for health uphold human right standards, including privacy, confidentiality, non-discrimination, transparency, and accountability? What discourses and tensions are emerging in the politics of digitalization?
- Who is shaping the digital agenda in health? Civil society, including affected communities, plays a key role in governance of the global HIV and TB response. What is their role in the emerging governance of digital technologies and AI? Who speaks for community stakeholders in these mechanisms?
- How are digital technologies and AI for health being experienced by frontline civil society groups

and public interest lawyers in developing countries? What questions or concerns do they want to see addressed? How might their input help to shape digital technologies and AI in health?
- What is the empowerment potential for these new technologies in community-led monitoring, mobilization, and rights-based advocacy?
- What new challenges and opportunities will emerge for human rights of marginalized communities as AI develops in the future?

This paper explores these questions through human rights and legal analyses of digital technologies and AI in health. Given that the project is developed in a unique consortium that includes people living with HIV and AIDS activists, we see an opportunity to develop a deeper understanding of the human rights in digital health of concern to young women and marginalized groups, such as people who are living with or affected by HIV and TB, and key populations (gay men and other men who have sex with men, sex workers, transgender people, and people who use drugs) in low and middle-income countries. In addition to their vulnerabilities to HIV and TB, and the specific needs they have for sexual and reproductive health (SRH) services, these populations have been heavily impacted by the COVID-19 pandemic. Digital technologies and AI offer both unique opportunities and inherent risks.

This working paper sets out a conceptual framework that will inform our research and policy engagement, and examines how these concepts emerge in some global and regional guidelines and jurisprudence. A second inception paper maps laws, policies, and digital health interventions in Ghana, Kenya, and Vietnam, and is complemented by an internal stakeholder mapping to inform development of a theory of change for the project.

1.2 Conceptual Framework: Human Rights, Intersectionality, and Knowledge Production

Our conceptual framework is grounded in human rights, and is informed by related areas of thinking and work on intersectionality, decolonization, and community engagement. The framework is a living set of concepts that will evolve as the research progresses, weaving in concepts and empirical findings from the research and from our experience. We are especially interested in exploring and identifying practices in our work that can counter the inequalities we both document and experience in daily life, including through critical reflection on our engagement in global health governance, and through our ongoing work with communities living with and affected by HIV in Ghana, Kenya, and Vietnam.

We take the human rights framework in health as our starting point, while we also acknowledge the tensions and debates around this framework in the current historical moment. A significant body of research has established how human rights norms and standards shape health outcomes, particularly in relation to HIV and SRH rights (see, for example, evidence collated in two reports for the Global Commission on HIV and the Law, 2012 and 2018). More recent literature on human rights in the digital age explores how digital transformation affects the rights of young people, including an anticipated joint report from The Lancet & Financial Times Commission titled *Growing up in a digital world: Governing health futures 2030* (forthcoming October 2021).

All human rights are understood to be universal and interdependent; we focus especially on how intersecting forms of inequality affect the right to the highest attainable standard of physical and mental health. Article 12 of *The International Covenant on Economic, Social and Cultural Rights (ICESCR)* upholds this right, which is also articulated in other treaties. As elaborated by the Committee on Economic, Social and Cultural Rights ("the Committee") in General Comment no. 14, the normative content of the right to health includes ensuring availability, accessibility (including affordability), acceptability, and quality of health services, facilities, and care (also known as AAAQ) (UN CESCR 2000: article 12, para. 12).

While some states have more resources for health than others, all states are required to dedicate "maximum available resources" to health services, in order to progressively realize the right to health over time (ICESCR, article 12, para. 30). States must also meet certain minimum obligations, such as non-discrimination, regardless of resources. Global health financing mechanisms should also uphold these standards in their financing.

Human rights standards and tools thus offer one way to contest and challenge deep global power imbalances. The global movement of people living with HIV (PLHIV), women, and key populations have often utilized human rights in community mobilization and empowerment, and these tools have also been embraced by rights defenders in low and middle-income countries in their litigation and advocacy, a phenomenon described by Akoth, de Strooper and Merry, and others as a way of "vernacularizing" or localizing human rights in the postcolonial era (Akoth 2014, de Strooper and Merry 2018). Indeed, both Kenya and Ghana have enshrined human rights in their national constitutions.

At the same time, human rights institutions such as the International Criminal Court have also been criticized for replicating the inequalities of colonialism (Clarke 2019). The field of health and human rights, which developed over the past 30 years, has not been exempt from these inequalities; most of its leading voices are white male scholars and organizations headquartered in high-income countries.

Thus, in thinking through the specific barriers faced by women and marginalized groups in fulfilling AAAQ in the digital age, we will utilize intersectionality, an approach that considers the multiple ways in which power is unevenly exercised through intersecting social forces and identities (Crenshaw 2017). We are also inspired by a growing body of work calling for decolonization of global health in order to address historical geographic inequalities and create "an equal, inclusive, just, and diverse global health architecture" (Abimbola and Pai 2020).

We are interested in how these forms of inequality intersect to shape visibility and invisibility in data, resulting in people, issues and realities being left "uncounted" in global health, with resulting biases reinforced and amplified by algorithms (Davis 2020). These diverse forms of inequality also come together to create what Bhakuni and Abimbola call "epistemic injustice", in which knowledge in global health is constructed by and serves the needs of those in power, while the "knowledge held by people who belong to marginalized groups…is systematically afforded less credibility", resulting in "distinct wrongs to a person in their capacity as knower" (Bhakuni and Abimbola 2021).

Our collaboration builds on this analysis to explore visions of what "epistemic justice" might look like in practice. One of the rights we draw on, discussed further in this paper, is the right to participation, which is dependent on other civil and political rights, such as the right to freedom of expression, and the right to freedom of assembly and association. The right to participation is championed at all levels of the global HIV response, including through seats and votes in global health governance, but what it might look like in the digital age is still being debated.

As we reflect on the possibilities, and as discussed further in this paper, we seek to study and apply diverse approaches to participation, by reflecting on inequalities within our own consortium and reflecting on measures we can take to address them.

Ultimately, we see the rise of digitization in global health as demanding new, twenty-first-century thinking about how to change the governance of digital technologies and AI in health. We will build on thinking and lessons learned from the twentieth century while drawing from diverse sources to ultimately move towards more democratic, just, and effective approaches to health in the digital age.

Using this emergent conceptual framework, this paper explores the following issues:

→ Inequalities emerging in digital health;
→ The human right to non-discrimination;
→ Risks and opportunities for young women and marginalized groups in digital transformation of health;
→ How these issues are addressed in regional mechanisms, national jurisprudence, UN guidance and ethical principles; and
→ How the human right to participation might be used to counter these inequalities in digital health.

2 | INEQUALITIES IN DIGITAL HEALTH

The COVID-19 pandemic has laid bare the landscape of deep social, economic and political inequalities, in which digital health interventions are implemented and brought to scale. This is a landscape already all too familiar to those working in (or living with) the global response to HIV and TB, and witnessing the impact of those two epidemics on young people in low and middle-income countries. Digital divides mirror these broader socio-economic divides: between and within countries; between genders, generations, and across social groups (WHO 2020). Robust digital health governance must consider and address the disproportionate impact of potential harms these new technologies produce for young people — especially those who have historically experienced marginalization and discrimination — and maximize the empowerment potential of these tools.

While there are many forms of inequality and discrimination in every society, as discussed below, the specific inequalities considered by this project are:

→ The digital gender divide
→ Inequalities for marginalized groups
→ Colonial legacies

2.1 The Digital Gender Divide

COVID-19 has both highlighted and deepened existing gender inequalities in digital technologies. Women, including transgender women, face a digital gender divide for several reasons (OECD 2018).

First, they have less access to education and employment than their cisgender male peers in most societies. Societal biases (the widespread idea that technology is for boys) and lack of access to tech education means that digital literacy is overall lower among women and girls, creating what UNICEF calls a “learning crisis” for girls in Science, Technology, Engineering and Mathematics (STEM) subjects. UNICEF and ITU report that “girls in low and middle-income countries are particularly disadvantaged in developing digital skills” (UNICEF and ITU 2020: 13). Women of color are particularly under-represented in STEM subjects.

Second, women are also less likely to have access to digital technologies than their male peers. According to the global association of mobile operators, over 300 million fewer women than men access the internet through a mobile phone (UNICEF and ITU 2020: 13). Women globally are less likely than men to use the internet to download software, or to buy or sell goods online; the gender gap is widest in the South Asia region, followed by sub-Saharan Africa. Little (if any) research appears to have been done yet about access to the internet and digital technologies for transgender people.

Third, as a result of these two factors—inequality in education and unequal access—girls are significantly less likely to consider a career in tech than boys: at 15 years of age, only 0.5% of girls aspire to become tech professionals, compared to 5% of boys (OECD 2018). Only 26% of those working in data and AI are women, and only 12% of those in cloud computing (WEF 2020). Only 21% of technology executives are women, due to a combination of factors which women say include lack of female role models, the gender pay gap, and persistent gender bias (ISACA 2017). Studies of those employed in the tech sector find they report widespread gender and racial discrimination, resulting in burnout (Marchant 2021).

Taken together, these factors create a picture of a sector that is dominated by cisgender men, with few openings and limited uptake for women in all their diversity. Indeed, in practice, mobile health interventions have shown higher rates of success with men than women: for example, in Uganda, men participated twice as often as women in an SMS text message-based campaign on HIV prevention; and in the Democratic Republic of Congo, over 80% of callers on a family planning hotline were male (Chib et. al. 2012; Corker 2010). To combat the digital gender divide, UN member states have committed to increasing women and girls' access to technologies as part of Sustainable Development Goal Five.

As discussed in the next section, these inequalities can be worsened for women and girls who are also members of other marginalized groups.

2.2 Inequalities for Marginalized Groups

People living with HIV and affected by TB, as well as key populations at greater risk of both HIV and TB, face widespread and systematic discrimination in all areas of employment, education, housing, and access to health services (Global Commission on HIV and the Law 2012, 2018). Other disadvantaged groups, such as persons with disabilities, migrants, and indigenous people, also experience structural inequalities which, especially when combined with lack of access to underlying social determinants of health such as clean water and safe housing, increase their vulnerability to HIV and TB. These structural factors similarly create unequal access to digital technologies and the internet.

Discrimination is widely documented against PLHIV, and can include discriminatory treatment by healthcare providers. TB affects those who are impoverished and marginalized, including PLHIV, people who use drugs, mobile populations, the rural and urban poor, miners, prisoners, and women and children; and stigma related to TB can also impede people's access to testing and other tuberculosis services (UNDP 2014). Moreover, active case-finding and digital adherence technologies could create unique data risks and threats to persons affected by TB, many of whom also belong to vulnerable and marginalized groups (Albrecht and Citro 2020). Given the risk of discrimination, PLHIV and people affected by TB face specific risks in cases of data breaches, including risk of exposure in their communities leading to loss of housing, employment, and risk of violence.

Criminalization creates added vulnerabilities for key populations most at risk of HIV. Seventy-three countries criminalize same-sex sexual acts, and most countries criminalize sex work and drug use; few countries recognize a legal change of gender identity (UNAIDS 2021, ILGA 2020). Criminalization combines with stigma to drive key populations away from government health services in many settings. In addition, it increases the likelihood that key populations may be targeted for police surveillance, including through facial recognition software and surveillance on their mobile phones (HRW 2020).

Given these structural factors, many PLHIV, and key populations also face economic marginalization; many can only find employment in the informal economy. This lack of stable income naturally limits their access to technology and the internet; in particular, where there is no publicly-accessible wifi, a given user's access to the internet may be limited by the number of minutes he/she can afford to buy on a shared mobile phone. During the COVID-19 crisis, millions of those employed in the informal economy experienced even greater economic precarity. The disruptions caused by COVID-19 have created stockouts in antiretroviral treatment, interruptions in income, and diminished access to social protection in many countries; the crisis has been even worse for indigenous and tribal people who are living with HIV and thus particularly vulnerable to COVID-19 and its socio-economic consequences (ILO 2020).

The devastating effects of the pandemic are likely to only widen digital divides for women, girls, and marginalized groups. When access to smartphones or internet use is required, they could face insurmountable barriers to government-funded health services, and privacy is of greater importance for these populations.

2.3 Geopolitical Inequalities

A third form of inequality shaping digitization relates to historical, political, and economic imbalances among countries due to the legacies of colonialism (Khan et. al. 2021). As many of the largest tech companies are headquartered in the U.S., imbalances in production and consumption of the data needed to develop, train, and improve AI-enabled digital technologies in health create the risk of exploitation of young adults in low and middle-income countries, a phenomenon some call "data colonialism" (Couldry and Mejias 2019).

Digital health could perpetuate these inequalities, by opening up the most intimate and private information about young adults in low and middle-income countries for extraction, in order to generate profits in high-income countries. At the same time, new centers of power emerging in the digital age, such as China, could shift these geopolitical power dynamics in unpredictable ways.

2.4 The Right to Non-Discrimination

In considering the above intersecting forms of inequality, the human rights framework offers important normative standards. Non-discrimination is fundamental to human rights law, and is affirmed in the beginning of each human rights covenant, including in the right to health. General Comment 14 on the right to health, referenced above, emphasizes that health facilities, goods and services must be accessible to all, "especially the most vulnerable or marginalized", without discrimination (CESCR 2000). The grounds on which discrimination is prohibited include "race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status" (UN human rights treaty bodies have affirmed that "other status" includes sexual orientation and gender identity).[1]

General Comment 20, on the right to non-discrimination in economic, social and cultural rights, further elaborates what non-discrimination means in practice. It distinguishes between *direct* and *indirect discrimination*, and clarifies that direct discrimination occurs when an individual is treated less favorably than another person in a similar situation for a reason related to a prohibited ground; while indirect discrimination describes laws, policies, or practices which may appear neutral at face value, but which have a disproportionate impact on rights of certain groups.

Digital technologies in health can thus promote either *direct discrimination*, for instance, through using biased algorithms; or *indirect discrimination*, for instance, if access to health services is reliant on the use of smartphones that people cannot afford to buy, or relies on digital literacy that they have never been taught.

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[1] Including the United Nations Human Rights Committee, the Committee on Economic, Social and Cultural Rights, the Committee on the Rights of the Child, the Committee against Torture, and the Committee on the Elimination of Discrimination against Women.

Ensuring these intersecting inequalities are addressed requires thoughtful, rights-based governance. This is underscored in two important new forms of UN guidance: the UNDP *Guidance on the Rights-based and Ethical Use of Digital Technologies in HIV and Health Programmes*, which notes the obligation on states to “proactively identify risks to non-discrimination in access and availability of technologies” and take measures to address them; and WHO’s *Ethics and Governance of Artificial Intelligence for Health*, which warns of the risk of discriminatory algorithms in digital health, and recommends states do impact assessments in order to identify and mitigate these risks (UNDP 2021: 17-18; WHO 2021: 88).

These recommendations will be discussed toward the end of the paper. We first move on to explore how the intersecting forms of inequality discussed above may play out in the digital transformation in health.

3 | RISKS AND OPPORTUNITIES IN DIGITAL HEALTH

Digital health could expose women and marginalized groups to disproportionate harm in three stages of digitization: as health systems move from paper records to digitization; from digitization to data systems; and from data systems to use of AI. At the same time, these tools offer significant empowerment potential as well.

3.1 The Transition to Digitization

As countries begin to gather data and use it to determine eligibility for services, access to health services may be impeded for groups dealing with widespread and deepening (in the COVID-19 pandemic) social and economic marginalization. Women, PLHIV, people affected by TB, and key populations may find it more difficult to access health information or services than their peers if they lack secure and private access to smartphones or the internet, or are unable to navigate these spaces effectively.

This has already emerged in several cases in the transition to digital identity systems for health service access. For example, Uganda's emergency relief program for COVID-19 relies on a national digital ID system that requires users to register online. As a result, women, persons living in poverty, older adults, persons with disabilities, and those living in remote rural areas (many in urgent need of economic assistance) have faced difficulties in accessing relief (Mukasa et. al. 2021, Center for Human Rights and Global Justice et. al. 2021). These risks in access due to digitization are increasingly being considered by courts in some jurisdictions, as discussed later on in this paper. A related research project, the Digital Welfare State and Human Rights Project at New York University, is investigating the impacts of digitization of social protection and welfare in many countries, in order to understand the impact of this transformation on human rights norms (Center for Human Rights and Global Justice 2021).

3.2 From Digitization to Data Systems

As digitized data begins to increase in quantity, and is gathered and shared across systems in order to facilitate more efficient and targeted health service management and national planning, new risks also emerge for women and marginalized groups.

On the one hand, a frequent lack of data on women's health needs, and lack of gender-disaggregated data in health more broadly, means that national priorities and plans fail to account for the specific needs of women and girls, and thus fail to uphold their right to health. A report to the UN Human Rights Council by the Independent Expert on Sexual Orientation and Gender Identity underscores that "disaggregation of data that allows a comparison of population groups… forms part of the human rights obligations of States and has become an element of the human rights-based approach to data" (Human Rights Council 2019).

At the same time, violations of the right to privacy and poor data protection raise disproportionate risk of harm to groups that face the discrimination, stigma, and criminalization discussed above.

Gender-based violence is widespread: at least one in three women have ever experienced physical and/or sexual violence (UN Women n.d.). UNWomen (2020) has reported higher rates of violence against women and girls online during COVID-19. As new outbreaks and epidemics sometimes trigger fear, as well as lead to new laws that criminalize transmission, members of the public may draw inferences—whether correct or mistaken—in an effort to pinpoint blame. For instance, women who are identified on online COVID-19 contact tracing maps as having circulated in public at certain places and times, have sometimes been accused of being sex workers, or of having affairs, which are accusations that could expose them to violence at home (Davis 2021).

Stigma linked to sexual orientation and gender identity also creates vulnerabilities to violence when privacy is breached online. For instance, in India, gay men and sex workers reported being stalked through online activities and threatened or blackmailed (Malnad et. al. 2020). In Morocco, gay men reported that they were targeted through an online harassment campaign; while in Egypt, police reportedly used dating apps to entrap LGBT people for arrest and abuse (HRW 2020, Corner n.d.). In Kenya, key population groups objected to biometric data-gathering for an HIV study, out of fear that given criminalization of key populations behavior, police could gain access to health data and use it to target individuals for arrest (KELIN and KP Consortium 2018).

The International Committee of the Red Cross (ICRC) has highlighted risks that states or non-state actors could use data gathered for humanitarian purposes to target individuals or groups for harm (Hayes and Marelli 2019). In addition, young women can be targeted online by anti-abortion organizations in efforts to constrain or manipulate their sexual and reproductive health choices (Privacy International 2019). More recently, the Pegasys investigations have revealed that human rights advocates, journalists and lawyers in many countries have been targeted with spying software that hacks even encrypted messages (Kirchgaessner et. al. 2021).

The *International Covenant on Civil and Political Rights* (ICCPR) recognizes the inherent dignity of all persons and upholds the right to privacy (General Assembly 1966: article 17). The Committee on Economic, Social and Cultural Rights (CESCR) has emphasized the right of everyone to control their own health and body, including their sexual and reproductive freedom; and has underscored the right to be free from torture, non-consensual medical treatment and experimentation (CESCR 2000: article 12, para. 8). A series of reports by the UN Special Rapporteur on Promotion and Protection of the Right to Freedom of Opinion and Expression, David Kaye, have highlighted the use of technologies to violate privacy rights (UN HRC 2019). In 2013, the UN General Assembly adopted resolution 68/167, expressing deep concern about the negative impact of surveillance on human rights. The Global Commission on HIV and the Law (2018) has raised related concerns about data protection in the context of the HIV response.

A growing number of countries have new data privacy laws, which vary in strength. Some address only minimal data protections, while others are more comprehensive; enforcement is uneven, as many citizens may be unaware of the risks or of their rights, and some data agencies are under-resourced to ensure even strong laws are upheld (Greenleaf 2019, Jervin 2013). The European Union General Data Protection Regulation (EU GDPR) is often cited as a potential model and is increasingly being considered by other countries. The EU's single market allows for development of uniform regulations, unlike other regional counterparts, but adherence still varies among European countries.[2] Given the recent revelations of hacking spyware in Europe, it is clear that even relatively robust European regulation is not strong enough to keep up with current technological advances.

In sum, while many countries are digitizing and thus rapidly increasing the quality and quantity of health data they gather, especially in response to the COVID-19 pandemic, weak and uneven regulation of data protection could expose women and marginalized groups to disproportionate risks in cases where a data breach occurs.

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[2] The EU GDPR has three objectives: to protect natural persons with regard to the processing of data; protect the rights and freedoms of natural persons with regard to their personal data; and guarantee the free movement of personal data within the EU (European Union 2016, chapter 3). It provides a harmonised framework for the protection of personal data; the processing of personal data; and the penalties for breach of the GDPR that apply to member states. It creates unified provisions on data processing for both public and private actors, restricting how both can gather and use individual data. It also imposes high fines on violations. In addition, GDPR emphasizes transparency and accountability: it gives individuals rights to be informed, to access the data, to rectify it, to erase it, to restrict processing, the right to data portability, right to object, and rights in relation to automated decisions and to profiling (Wolford 2020). One scholarly review of mobile apps for health found discrepancies between the information provided to users, and how apps actually used private health data, to make the argument that "opting out" of data-gathering should be a fundamental right (Kuntsman, Miyake and Martin 2019). Additional policy frameworks include: Directive 2002/58/ EC concerning the processing of personal data and the protection of privacy in the electronics communications centre; and Directive 2016/1148 on Network and Security Information.

In response to these inequalities in data governance, Heidari and Doyle propose what they call "a feminist approach to health data", using approaches that "emphasize the participation of women and other marginalized communities to inform methodological and analytic decisions on which data are to be collected and how, striving for this engagement to be emancipatory and the benefits reciprocal" (Heidari and Doyle 2020). Such approaches could offer space to these groups to understand the data, interpret the meanings that these findings have for their lives, and guide how this knowledge could inform investments, strategies, and programmatic decisions in a way that is relevant to their needs. Participatory processes can also engage communities in addressing the gender, decolonial, and ethical issues pertaining to data protection, privacy, and confidentiality (Ibid.).

Similarly, the new UN Political Declaration on HIV and AIDS has committed to increasing community engagement in research, which opens up the potential to develop more democratized (or feminist) approaches to data-gathering in health.

3.3 From Data Systems to Artificial Intelligence

As countries begin to transition from data systems into increasing reliance on AI-enabled technologies, a third set of risks appear for young women and marginalized groups. Biases encoded at the data-gathering stage can in turn produce biased decisions that deepen inequalities, and that manipulate users in ways that cause harm.

AI is a process or set of rules used by computers, known as an algorithm, to categorise and process data, identify patterns, and make predictions or decisions by analyzing data. However, the results are only as good as the assumptions used to design the algorithms, and the data sets used to train them. In distinguishing between indirect and direct discrimination, General Comment 20 asserts that "direct discrimination occurs when an individual is treated less favourably than another person in a similar situation for a reason related to a prohibited ground". Direct discrimination may occur in digital health as a result of algorithmic biases.

Many who design and use AI assume it is neutral and objective—but in practice, gender, racial and other biases have emerged due to the lack of diversity among designers, flawed assumptions and classification systems used to process the data, and gaps in data sets (Andersen 2018). The UN Special Rapporteur on Contemporary Forms of Racism, Racial Discrimination, Xenophobia and Related Intolerance has highlighted examples of algorithmic racial discrimination, including facial recognition algorithms that "were 10 to 100 times more likely to inaccurately identify a photograph of a Black or East Asian face, compared with a white one", because the data sets on which they were trained lacked diversity (Human Rights Council 2020). Similarly, another study of AI used for computer-based medical diagnosis performed less well on under-represented genders (Larrazabal 2020). This is unsurprising given that a recent study of AI used to tailor preventative and therapeutic treatments found that the most widely-used biomedical AI technologies ignored sex and gender, and the impact of these on health and disease (Cirillo 2020).

Biased data encodes conscious or unconscious societal biases into algorithms, reinforcing discrimination based on race, sex, gender, sexual orientation, age or poverty (Panait 2020). This includes biased datasets that result from structural factors: for instance, the avoidance of documentation by criminalized key populations and other groups at risk of arrest, who are often “the uncounted” in health data (Davis 2020). Criminalization and official negation can create a data paradox in which denialism leads to lack of data, resulting in lack of resources allocated to meet health needs, in turn reinforcing the lack of data (Baral and Greenall 2013). Gay men and other men who have sex with men may be undercounted or uncounted altogether in HIV studies in countries where same-sex sexual acts are criminalized and where convictions are punished with imprisonment, heavy fines, or even the death penalty. The same is true for transgender people; despite their high degree of vulnerability to HIV, most countries lack official data on their needs (Davis 2020). Such unrepresentative data sets have been called ‘health data poverty’ (Ibrahim et. al. 2020). The result can be algorithms that produce discriminatory recommendations.

In addition, algorithms can cause direct harm to the physical and mental health of young adults, because they are designed to capture and keep the attention of young people online, and to increase their time and exposure to targeted products and interaction with promoted sites. Research by 5Rights Foundation into the risks for children in digital design finds that children report harm as a result, due to the length of time they spend online, the negative experiences they have on social media, the eating disorders, depression, and abusive online relationships that result, and the intrusive targeting they experience (5Rights 2021).

3.4 Opportunities to Combat Inequalities

Notwithstanding these real concerns, digital health also offers positive opportunities to actively overcome social inequalities and marginalization, and to improve access to health services for those most marginalized.

For example, in Vietnam, a mobile app improved ethnic minority women’s access to maternal health services, and reportedly even helped build trust, strengthening their relationships with healthcare providers (McBride et. al. 2018). In Thailand, a low-cost, community-led social network of men who have sex with men and transgender people enabled community experts to share health information, social support, and legal advice on incidents of violence, discrimination, and abuse (Chaiyit and Walsh 2012).

A growing body of studies show that mobile health can extend health service coverage in rural and hard-to-reach areas, helping to reach “the last mile” of those who face difficulties in accessing the formal health system or essential health information. Women and girls living in areas where there are few clinics and poor transportation or roads, may benefit from even relatively simple digital health tools to gain needed sexual and reproductive rights information. For example, in the Philippines, in response to women’s lack of access to SRH services during the COVID-19 pandemic, health officials set up a hotline to answer questions by SMS text messages, and supplemented this with radio programmes and public video conferences (Philippines Humanitarian Country Team 2020). In Peru, pregnant women received customised health information through a project that linked electronic health records and SMS messages (Perez-Lu, Bayer & Iguiniz-Romero 2018).

Mobile apps that track supply chains could also permit civil society groups to monitor and report on HIV and TB treatment stockouts. Some mHealth interventions have demonstrated that social accountability through digital tools actually helps to build relationships between marginalized communities and the health sector: for example, an mHealth intervention in Ethiopia, designed in an iterative way with community input, strengthened accountability of health providers to the community, as well as strengthened incentives and other support to the health workers themselves (Mengesha et. al. 2018).

To sum up the argument so far, we have drawn on human rights norms and standards, as well as on literature on feminism, intersectionality, and decolonization, to think through some of the ways in which structural inequalities — gender inequality, racism, stigma and discrimination, criminalization, and colonial legacies to name several — may intersect to shape the digital world for young women and marginalized groups at three stages of the digital transformation. The specific human rights standards we have discussed include:

- Right to non-discrimination
- Right to the highest attainable standard of physical and mental health
- Right to privacy

At the same time, these tools offer real empowerment potential for women and marginalized groups. To maximize their transformative potential, states must be able to regulate them effectively. However, new technologies in health have raised complex challenges for officials and courts.

4 | HUMAN RIGHTS IN EMERGING GOVERNANCE OF DIGITAL HEALTH

How, then, are the above concerns addressed in national laws and jurisprudence, in regional human rights mechanisms, and in UN guidelines? Digital health governance is evolving, and an initial review of the field identifies some advances that address these concerns, but much more work is needed in order to protect the rights of women and marginalized groups. The following overview is not intended to be comprehensive. Rather, it aims to give a broad overview of the state of the field — one that is changing rapidly.

4.1 Key Jurisprudence in National Courts

Under international human rights law, states have an important role as duty-bearers to uphold human rights standards through governance and in the courts. In fact, courts may wind up on the front lines of policymaking in digital health governance, given that they are the first recourse for someone harmed by a private company.

Four significant cases have been decided that can guide this project's analysis of the impact of technology on the protection of the privacy and dignity of persons; though they do not address the specific concerns identified above, they do begin to consider the broader principles. These cases, while in four significantly different contexts (India, Jamaica, Mauritius, and Kenya), are indicative of the global impact of advances in technology. All four are centered around national policy on the collection of individual data. The courts considered the rights implicated by systems that utilise technology to improve service delivery and evidence-based interventions.

It must be noted that a number of rights were discussed by these courts; but all four turned to some degree on rights relevant to this project:

a. Right to privacy;
b. Right to dignity;
c. Right to equality and non-discrimination; and
d. Socio-economic rights (which include the right to health).

We discuss each below, and how they were interpreted in the four decisions.

A. THE RIGHT TO PRIVACY

The right to privacy was the cornerstone of each of the decisions, with the four courts basing their decisions on this right and what it entails.

The Supreme Court of India, in *Justice K.S. Puttaswamy (Retd) v Union of India and Others* Petition (Civil) No. 494 of 2012, considered this right in a petition centered on the Aadhar Card. The Aadhar Card was issued by the Unique Identification Authority of India under the Targeted Delivery of Financial and Other Subsidies, Benefits and Services Act, 2016. The Aadhar Scheme was conceptualized in 2006, and enacted in 2009, but only received statutory shield in 2016. Aadhar's purpose was to provide a systematic way to identify and verify recipients of subsidies and benefits from the State. While Aadhar was originally voluntary, over time it became in effect mandatory and a barrier to access state services.

While the Supreme Court eventually found that the Scheme was not unconstitutional, the framing of the right to privacy through this case offers valuable insights into the nature of that right in the digital age.

The *Constitution of India* does not explicitly recognise the right to privacy; so the matter was decided in two decisions. The first was to determine whether privacy is indeed a right protected by the Constitution.

On the question of privacy as a fundamental right, the Court in the first decision resoundingly answered with a "yes", noting that "(a) Privacy is concomitant of the right of the individual to exercise control over his or her personality, and (b) *Privacy is the necessary condition precedent to the enjoyment of any guarantees in Part III"*. With this finding, the Court underscored that fundamental rights and freedoms such as life, dignity, and equality cannot be enjoyed without respect for the right to privacy; thus, it is implicitly included in the enjoyment of all fundamental rights.

The Court unpacked the right to privacy in the following dictum:

> The fundamental right to privacy would cover at least three aspects:
> (i) intrusion with an individual's physical body;
> (ii) informational privacy; and
> (iii) privacy of choice.

(d) One aspect of privacy is the right to control the dissemination of personal information. Every individual should have a right to exercise control over his/her own life and image as portrayed in the world, and to control commercial use of his/her identity (Supreme Court of India 2018: para. 81).

Notably, these three interrelated and connected aspects of privacy included respect for one's physical integrity, freedom and choice, and the right to control the dissemination of personal information, which are aspects that can be significantly hindered when data is not in one's control or is easily copied. The Court went further, referencing the dystopian society imagined by George Orwell in *1984*, noting:

> Today, it can be a reality. The technological development today can enable not only the State, but also big corporations and private entities, to be the 'big brother' (Ibid. para. 594).

In a similar case, the Supreme Court of Jamaica, in *Julian Robinson v The Attorney General of Jamaica Claim* No. 2018HCV01788, 2019, also considered the issue of privacy (Supreme Court of Judicature of Jamaica 2019). The Robinson case focused on the National Identification Registration Act (NIRA) 2017, which was enacted in Jamaica to, among other things, facilitate the enrollment of all Jamaican citizens and persons ordinarily resident in Jamaica, in a National Identification System, and to provide for the verification of identities utilising this system.[3] The process of enrollment required the collection of biographical information (provided voluntarily), as well as biometric and demographic information.[4] Enrollment in the national identification system was mandatory for all citizens and residents, and the penalty for failure to enroll was criminal sanction.

The NIRA also mandated public agencies to require the submission of a National Identification Card (NIC) (obtained after enrollment and assignment of a unique number) to facilitate access to goods and services. Private agencies were not obliged to require the NIC, but they had the option to do so.

As with Aadhar in India, the right to privacy was the cornerstone of this decision as well. The three-

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[3] In 2021 Jamaica passed the National Identification and Registration Act, 2021 which through Section 38 repealed the 2017 version of the Act. For purposes of this discussion we shall focus on the 2017 Act which was the subject of the judgment.

[4] The Third Schedule of the NIRA biographical data includes: full names (or any name if changed via deed poll); date and time of birth; place of birth; full names of mother and father (where available); sex; height, principal place of residence; mailing address; nationality; period of residence (for non-citizens); details of marriage; details of divorce; and details of death. An email address was optionally required. Biometric data includes: photograph, finger prints, eye colour and manual signature (if over 18). Any one of the following may be collected—retina or iris scan; vein pattern; any one or two of the following—footprint, toe print or palm print. Any distinguishing feature or blood could optionally be included. Finally, within the same schedule demographic data includes: employment status, race, religion, education, profession, occupation, address of matrimonial home, telephone number, and sex. (Supreme Court of Jamaica: Para 42).

judge bench wrote separate concurring judgments and unanimously found that the NIRA was unconstitutional, in that it violated rights and freedoms under the Jamaican Charter. The following dicta is incisive of the crux of the case:

> Failure to provide adequate protection for the data is an exceptionally serious matter that rises to the level of a constitutional violation of the right to privacy...biometric features have five qualities that make them desirable to be used for identification and authentication. These qualities are (a) robustness, (b) distinctiveness, (c) availability, (d) accessibility, and (e) acceptability (Supreme Court of Jamaica 2019: para. 45).

The Court noted that while biometric systems are valuable in ensuring precision and accuracy in identification of persons, the combination of data with algorithms in the age of AI makes it possible to generate facts otherwise not known, which may not be needed or relevant for the purpose of identification (Supreme Court of Jamaica 2019: para. 238). Self-learning machines, which can create new knowledge without any programming, can access combined data (biometric, biographical and demographic) and utilise this to develop new information on persons, going beyond the original intended purpose of the data-gathering.

Having established the nature of these systems and their possible impact, the Court considered the issue of privacy, relying on the Indian Supreme Court’s above-mentioned decision to note:

> Privacy, as now understood, has at least three different aspects: privacy of the person, informational privacy, and privacy of choice. These aspects of privacy arise not because they are conferred by the State but are possessed by all persons simply by being human (Supreme Court of Jamaica 2019: para. 175).

The Jamaican Court went on to find that the enrollment and verification system was a violation of the right to privacy as enshrined in the Jamaican Charter. It found that the State had failed to provide the necessary robust framework to protect the right to privacy.

Similarly, a third court decision from Mauritius in *Madhewoo M. v The State of Mauritius and Another* 2015 (SCJ) 177 centered on the enactment of the National Identity Cards Act, 2013, which enabled the State to issue unique identifiers using biometric and biographical information (Madhewoo M. v The State of Mauritius and Anor 2015).

While the Supreme Court in Mauritius did not find the collection of this data to be unconstitutional or a breach of privacy, it did note that appropriate safeguards were needed to ensure that data was protected. Its analysis of the Data Protection Act found that the legal exemptions allowed ready access to personal data of the plaintiffs "in a large number of situations". (Madhewoo M. v The State of Mauritius and Anor 2015: supra note 7, page 33). Thus, any State exercise to obtain and store personal data must be accompanied by a system that protects that data from unwanted intrusion, something that Mauritius had failed to do.

Finally, we turn to Kenya. The High Court in Kenya was called upon to interrogate the constitutionality of the amendments to the Registration of Persons Act, Chapter 107 of the Laws of Kenya, and the subsequent introduction of the National Integrated Information Management System (NIIMS) in *Nubian Rights Forum and two others v The Attorney General and 7 others; Child Welfare Society and 8 other interested parties* Consolidated Petitions 56, 58 and 59 of 2019 *(Huduma Number Case)* (High Court of Kenya 2019).[5] Like the other cases discussed above, the Kenya case also turned on the collection of biometric data for the registration and enrollment of persons that are Kenyan, or ordinarily resident in Kenya, using a national identification system.

The distinction in the Kenyan case is that unlike India, The Constitution of Kenya, 2010, recognises the right to privacy. This right is enshrined in Article 31, which states:

> Every person has the right to privacy, which includes the right not to have (a) their person, home or property searched, (b) their possessions seized, (c) information relating to their private affairs unnecessarily required or revealed, and (d) the privacy of their communication infringed (Republic of Kenya 2010: Article 31).

Relying on this constitutional provision, the Kenyan Court interrogated the NIIMS, considering the data it required, the purpose of its collection, and the proportionality of those measures. The Court found that the issues in the case fell within the scope of informational privacy as protected by Article 31(c), noting that the scope of this right guarantees control over personal information (High Court of Kenya 2019: para. 749).

In seeking to answer the question of whether or not the right to privacy had been infringed the Court held:

> It is also notable that in Article 31 (c) of the Constitution, a violation of the right to informational privacy occurs when personal information is unnecessarily required or revealed. Therefore, the outstanding question before us is whether the requirement of, and collection of biometric data was necessary or not (High Court of Kenya 2019: para. 774).

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[5] Amendments to the Registration of Persons Act in Kenya was through the Statute Law (Miscellaneous Amendment) Act No. 18 of 2018.

In answering this question, the Court looked at the types of data to be collected under NIIMS. It found that unique identifiers such as fingerprints, hand geometry, earlobe geometry, retina and iris patterns, and voice waves, could all be collected for the reasonable implementation of NIIMS. However, the collection of DNA and GPS coordinates was found to be intrusive and unnecessary, and thus a violation of the constitutional right to privacy (High Court of Kenya 2019: para. 784).

Thus, from the above analysis of the four cases in India, Jamaica, Mauritius, and Kenya, it is clear that courts have found that the right to privacy speaks to three interrelated elements: physical integrity (protection against physical intrusion); informational privacy (the right to choose if and when to share personal information); and privacy of choice (individual autonomy). These three aspects form components of the right to privacy and are fundamental to the realisation of other rights. However, while they agreed on the components of the right to privacy, the four courts differed in their assessments of whether national identification systems, including systems that gathered biometric data, and existing protections for data collected, violated that right.

B. THE RIGHT TO DIGNITY

The Supreme Court of India found itself in a unique position in determining the case of the Aadhar Scheme because as discussed above, the right to privacy is not explicitly mentioned in the Indian Constitution. In reaching the decision that the right to privacy is implicitly included in the Constitution, the Court noted that privacy is implicit in freedom, liberty, and dignity. The Court in the Aadhar Scheme case went further, and held that the right of choice and self-determination are accepted parts of human dignity.

In unpacking this right to dignity, the Court considered the aspects of dignity, which it found has three elements: intrinsic value, autonomy, and community value. The Court accepted that personal autonomy must be balanced against the ‘values, rights and morals’ of people, who are free and equal. The Court noted that within the Constitution of India, dignity is not a free-standing right, but a constitutional principle, which should be utilised in interpreting rights such as socio-economic rights. To this end, the court discussed all three aspects and found:

> Dignity as a community value, therefore, emphasises the role of the state and community in establishing collective goals and restrictions on individual freedoms and rights on behalf of a certain idea of the good life (Supreme Court of India: Para 116).

Within this framing, the question for the Court was not whether or not the State or community can interfere with personal autonomy in service of a collective goal, but whether or not such interference was legitimate within a democratic society. The majority in the Aadhar case ultimately decided tahat the scheme was not unconstitutional, because the sharing of biometric information was dependent upon the consent of the owner of that data. Thus, it found that the collective good in this instance outweighed the value of personal autonomy, since it considered that sufficient measures had been put in place to protect personal autonomy.

The *Robinson* case in Jamaica similarly considered dignity, and relied on the interpretation of the Supreme Court of India in unpacking the right to dignity, but came to a different conclusion. The nature of the Jamaican Act was that, unlike in India, one could be compelled to register, including through threat of criminal sanction. The Jamaican Court found this compulsion to be a violation of the right of security of the person and privacy, rights which are integral to and reflect human dignity (Supreme Court of Jamaica 2019: para. 349).

The right to choose whether or not to share information is thus understood to be an integral component of dignity, and while the Indian Court did not see dignity as violated by data-gathering because the scheme was designed to be voluntary, the Jamaican Court found that a mandatory provision, with no opt-out caveat, violates this right.

C. THE RIGHT TO EQUALITY BEFORE THE LAW (NON-DISCRIMINATION)

Two of the four cases, Jamaica and Kenya, also addressed the right to non-discrimination in digital systems, though they reached different conclusions.

The right to equal treatment before the law was significant in the *Robinson* case, with the petitioner alleging that the requirement that citizens and residents submit their NIC to access goods and services from public bodies violated the right to non-discrimination. The court considered whether this did amount to discrimination, and in seeking to answer this, sought to find whether differential treatment amounted to discrimination. The Court found that the provision required that Jamaicans (citizens and persons ordinarily residents) produce their NIC to obtain goods and services, and did not require the same for foreigners, or provide an exception if the Jamaicans in question could identify themselves using other methods.

The Court further considered the scope of the provision as it failed to define “goods and services” and thus, could arguably apply to legal entitlements. The Court could find no justification for the differentiation between Jamaicans and foreigners, and found that ‘a lack of jurisdiction’ over foreigners was not a compelling reason for this differentiation. The Court concluded that the differentiation amounted to discrimination, as there was no justifiable reason for it.

The right to non-discrimination was similarly debated in the *Huduma Number Case* in Kenya, with the first petitioner, the Nubian Rights Forum, arguing that the implementation of NIIMS would perpetuate discrimination against the Nubian community. The Nubian community are descendants of people from Sudan who were brought to Kenya under British colonialism, and have faced significant challenges in securing their rights as citizens, including obtaining identity cards, despite the community's presence in Kenya for over 100 years.

The first petitioner noted the extensive vetting processes Nubians are subjected to in seeking to obtain identification documents, rendering many members of the community stateless and undocumented. The petitioner argued that existing amendments would exacerbate these institutional problems (High Court of Kenya 2019: paras. 923-1003). The Court found that the framing of the legislation did not differentiate between Nubians and other Kenyan citizens of different ethnicity, and was thus not unconstitutional. The Court's finding was grounded on the neutrality of the provisions; the Court did not interrogate the issue of indirect discrimination, which was alluded to by the first and second petitioners.

D. LEGAL ENTITLEMENTS/SOCIO-ECONOMIC RIGHTS

How do digital systems affect social and economic rights? In 2019, UN Special Rapporteur on Extreme Poverty and Human Rights, Phillip Alston, cautioned that digital technologies could be a "trojan horse" for forces that seek to privatize social and economic services. In particular, he warned,

> 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 (General Assembly 2019: para. 5).

The issue of the impact of digital technologies on 'legal entitlements' to social services was significant in the Aadhar case in India, which broadly speaks to entitlements that accrue by law, such as education, water, health care, and other services as defined within each legal system. The *Aadhar* Scheme began, and was framed, as a voluntary scheme, but morphed into a more directive or mandatory scheme which had an impact on the ability of persons not registered to access some benefits.

Thus, the Court had to consider how to balance rights. Aadhar forces us to consider rights not as a zero-sum calculation, but as a delicate balance of competing and complementary interests which can and must co-exist. In considering the interaction between civil and political, and socio-economic rights the Supreme Court of India noted:

> In seeking to draw the balance between political freedoms and economic freedoms, the Court must preserve the euphony between fundamental rights and directive principles. It is on their coexistence that the edifice of the Constitution is founded. Neither can exist without the other. Democracy rejects the totalitarian option of recognising economic entitlements without political liberty.
>
> Economic rights have become justiciable because of the constitutional guarantees founded on freedom and the rule of law. The Constitution is founded on democratic governance and is based on the protection of individual freedom. Freedom comprehends both fundamental political freedoms as well as basic human rights (Supreme Court of India 2019: para. 194).

Legal entitlements are often framed as socio-economic rights, and the tools utilised to deliver these rights might sometimes be in conflict with other fundamental rights. The Aadhar Scheme required individual registration in order to access services which are legal entitlements. Thus, the Court had to consider whether the State could utilise the Aadhar mechanism to violate other rights, such as privacy and dignity, while justifying this as a policy decision in order to deliver on socio-economic rights. This, it was held, cannot be an acceptable state of affairs in a democracy—economic entitlements cannot be used as a trade-off for political liberty. Both must coexist, and while this may require some compromise or derogation, this must be justified.

The need for accurate data to inform decisions taken by states is not new; however, the age of digitization amplifies concerns because of the ease with which information can be replicated or repurposed. Data collection in any context requires significant appreciation of security and privacy. A rights-based approach to digital technology requires an unpacking of the rights implicated by digital technology. However, information stored digitally can easily be copied, replicated, and shared all outside of the control of the subject of that information. Digital technologies are significant in transforming access to health services and information, and bridging the inequities between and within nations. However, as the Supreme Court of India notes, the State and corporations can easily become all-powerful ‘Big Brothers’, and the dystopian state referenced by George Orwell could become a reality if countries apply technology without developing robust legal frameworks to protect the rights of persons.

The analysis of these four legal decisions elaborates on how the human rights principles discussed earlier in this paper may play out within diverse legal regimes and in specific cases. In particular, they show an emerging concern by the courts with the need for adequate regulation to ensure privacy and autonomy are adequately protected, a concern for non-discrimination in algorithmic decision-making, and a concern that fulfillment of socio-economic rights not be achieved at the expense of other rights that are fundamental to human dignity. This reasoning by the courts helps to underscore the fundamental nature of the rights analyzed in this paper, and can inform the research and recommendations by the Digital Health and Rights Project, as well as future thinking about how the rights these four decisions elaborate may be upheld for women and marginalized groups.

4.2 Regional Human Rights Mechanisms

While national courts contend with human rights in these specific cases, regional human rights bodies are also gradually beginning to address digital governance. The European Union has been in the forefront of developing new policies, with ambitious new programmes in this area under development in 2021, while the African Union is still in its early stages. The Association of Southeast Asian Nations (ASEAN) has not prioritized human rights and protection of persons, and this seems unlikely to change.

EUROPEAN UNION

The European Union (EU) is currently at the forefront of developing regulations to govern AI and digital technologies, through a "Digital Policy Programme" and Digital Principles. While they do not comprehensively address all the concerns described above, they do help to advance new norms that could form the basis for more robust digital governance in other regions. This work builds on the GDPR, a proposed Digital Services Act, and a proposed Regulation on AI all under development (European Commission 2021).

The draft Regulation on AI was shared in April 2021, and set out plans to significantly reform digital governance in the region. Among other provisions, it would require companies to meet standards for data and digital governance, transparency provisions for users, due diligence for "high risk" AI, and would prohibit practices that "have a significant potential to manipulate persons through subliminal techniques" (5Rights 2021a). A postmarket system would be required to detect and mitigate problems; however, critics note some significant gaps, including on calls to break up Big Tech, and address algorithmic discrimination, among other concerns (MacCarthy and Propp 2021). Nonetheless, it may be a first step towards a shared approach to governing tech within the U.S. and other countries.

The EU has, for the past two years, progressed towards establishing a Digital Services Act in order to regulate online platforms and digital services, "harmonizing a fragmented regulatory landscape in content governance," an effort AccessNow observes is actively being undermined by the development of national regimes by some EU member states (Pirkova 2021). In July 2021, 5Rights Foundation warned that the Digital Services Act was itself being undermined with weakened language on child protection (5Rights 2021).

In addition to these governance moves in the EU, the European Court of Justice has been called upon on a number of occasions to determine whether national laws (grounded in protecting security) can require an electronic communications provider to retain, indiscriminately, traffic and location data for purposes of national security and to combat crime. This question has been considered in: *Tele2 Sverige AB v Post-och Telestyrelsen and Secretary of State for the Home Department v Tom Watson and Others* Joined Cases C-203/15 and C-698/15 and more recently in *Privacy International v Secretary of State for Foreign and Commonwealth Affairs and Others* Case C-623/17 and *La Quadrature du Net and Others; French Data Network and Others;* and *Ordre des barreaux francophones et germanophone and Others* Joined Cases C-511/18, C-512/18 and C-520/18. These cases affirm the position that national laws are precluded from requiring electronic communications providers to retain traffic and location data indiscriminately, as it would be contrary to Directive 2002/58/EC.

More recently, however, the Court relaxed this position, holding that member states facing genuine and present or foreseeable security threats may derogate from the obligation to maintain confidentiality; however, this can only be done for a limited time period and for strictly necessary purposes. The EU approach to regulating digital technologies will continue to evolve in alignment with the EU Charter of fundamental rights, with the Digital Services Act under deliberation in the European Parliament and Council, but their ability to enforce new standards in member states remains in question.

AFRICAN UNION

The African Union (AU) has so far largely focused on the security threats linked to digital technologies. The *AU Convention on Cyber Security and Data Protection* was adopted in 2014 as part of the AU's 2063 agenda. This Convention has been signed by 14 member states and ratified by eight; thus it has not met the threshold to come into force, which is ratification by at least 15 member states. The Convention imposes an obligation on member states to establish legal and policy frameworks to promote cyber security governance and manage cyber crimes. The Convention does not seek to establish a harmonised regulatory framework across 55 states (recognising the divergence between the states and the lack of a single market), but provides an overarching framework around which states can develop their own frameworks that are aligned to the spirit of the Convention (Turiyankski 2020).

The Convention is thematically focused and arranged in three chapters: electronic commerce, protection of personal data, and cyber security. On protection of personal data, article 13 of the Convention underscores principles that should be included in national frameworks including: consent and legitimacy of data processing; lawfulness and fairness; purpose, relevance and storage of personal data; accuracy of data; and transparency in processing data.

If the Convention gains the force of law it would be subject to interpretation by the African Commission on Human and Peoples' Rights (the Commission) and the African Court on Human and Peoples' Rights (also limited to States that have ratified the Protocol and related instruments establishing its jurisdiction). The African Court is much younger than the Commission and has limited jurisdiction. Only ten countries have deposited declarations to the effect that the competence of the Court is recognised, and four of these have since withdrawn those declarations since. The Court has not pronounced itself on a number of these issues, but played a significant positive role in the case of the Ogiek people against the Government of Kenya (Minority Rights International Group 2017).

The Commission has taken a number of decisions that have protected the rights of vulnerable and marginalised groups, for example, in decisions against Egypt and Ethiopia that affirmed the States' positive duty to protect women and girls, the rights of minority communities, resolutions that sought to protect sexual and gender minorities from violence, and to protect the rights of PLHIV.[6] The commitment to protect marginalised and vulnerable communities has come into question, however, given such recent decisions as one to withdraw the observer status of the Coalition of African Lesbians (Article 19 2018). However, given its previous decisions and its positive engagement on rights of PLHIV, the Commission would be expected to approach decisions regarding this Convention through a rights lens, and would work to protect communities vulnerable to exploitation.

The AU has developed a Digital Transformation Strategy for 2020 through 2030, with the overall objective of "harnessing digital technologies and innovations to transform African societies and economies" (African Union 2019: 1). This strategy seeks to use technology to transform a number of sectors including health, and to secure a single digital market in Africa. The strategy commits to making digital identity part of a civil registration process, it is cognisant of human rights, and seeks to work in an environment with legal and policy frameworks that secure privacy, and protect data and consumers.

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[6] Egyptian Initiative for Personal Right and Interights v The Arab Republic of Egypt Communication No. 334/2006 was the first case centred on women's rights; the Commission has come under criticism for its failure to centre women in subsequent judgments including Equality Now and Ethiopia Women's Lawyers Association (EWLA) v Ethiopia Communication 341/2007, and Doebbler v Sudan Communication No. 235/2000. See also Centre for Minority Rights Development (Kenya) and Minority Rights Groups (on behalf of Endorois Welfare Council) v Kenya Communication No. 276/2003. The Commission has also passed Resolution 275 on Protection against Violence and other Human Rights Violations against Persons on the basis of their real or imputed Sexual Orientation and Gender Identity and a number of resolutions on HIV: Resolution 53 on the HIV/AIDS Pandemic threat against Human Rights and Humanity; Resolution 290 on the need to conduct a study on HIV, Human Rights and the Law; and Resolution 260 on Involuntary Sterilisation and the Protection of Human Rights in access to HIV services.

ASSOCIATION OF SOUTHEAST ASIAN NATIONS (ASEAN)

ASEAN was established by the Bangkok Declaration of 1967 and comprises ten countries geared towards political and security cooperation to enhance economic growth, social progress, and cultural development, and promote regional peace and stability through a respect for justice and the rule of law. To date, ASEAN has largely avoided addressing rights violations by member states. However, the 2008 ASEAN Charter does require that members respect fundamental freedoms, promote and respect human rights, and promote social justice. Article 14 of the Charter provides for the establishment of a regional human rights body, the ASEAN Intergovernmental Commission on Human Rights, which was founded in 2009. Unlike its counterparts in Africa and Europe, ASEAN does not have a developed human rights framework, and the mechanisms for the protection of human rights are nascent and not grounded on a codified bill of rights. While there is potential to protect human rights within the realm of digital technologies and cyber space, the current ASEAN literature does not reveal concern with these issues.

In sum, regional mechanisms provide an opportunity to both standardise norms and provide remedies when these standards and norms are breached. The EU has been able to do this most effectively because of the single market which has allowed for standardised norms — whether it promotes uptake of these norms in diverse states remains to be seen.

4.3 UN Guidance and Ethical Principles

While the courts and regional mechanisms have begun to consider these complex issues, more broadly, UN agencies have developed sets of principles for digital governance which address the issues raised in this paper: non-discrimination, the right to health, and privacy rights.

In June 2021, the UN Development Programme (UNDP) launched its *Guidance on the Rights-based and Ethical Use of Digital Technologies in HIV and Health Programmes*, followed within days by the World Health Organization (WHO)'s *Ethics and Governance of Artificial Intelligence for Health*. Both guidance documents were developed based on extensive literature review, as well as consultation with diverse stakeholders (including members of DRAG). While UNDP relies mostly on human rights law, but aims to align these with ethical principles, WHO relies solely on ethics. While the two guidance documents help to advance a collective understanding of rights in digital health, three questions could benefit from further reflection.

First, both guidance documents address the risks raised in this paper. To address these risks, both emphasize the importance of states and the private sector conducting human rights risk assessments before implementing or scaling up digital health technologies. This approach is consistent with that recommended by human rights experts (McGregor et. al. 2019). For example, the *UN Guiding Principles on Business and Human Rights*, which interprets the existing human rights standards for the private sector, clarifies that **the state's duty is to protect** against human rights abuses by third parties, including businesses; **corporations have a responsibility to respect** human rights, by doing due diligence in order to avoid infringing human rights, both through a corporation's own activities and through its value chain; and both the state and businesses have a responsibility to **ensure access to effective remedy** for victims, both through the courts and through non-judicial remedies (UN Office of the High Commissioner for Human Rights 2011). European Union guidance provides an interpretation of the UN Guiding Principles for the digital sector (EU 2014).

However, the Guiding Principles have been critiqued as limited by scholars and practitioners (McGregor et. al. 2019). The use of risk assessments in particular creates difficult questions: who is responsible for accountability once the risk assessment is done? Who has access to risk assessments, and how can they be evaluated? And from the perspective of officials, are risk assessments for digital health technologies potentially too onerous and expensive as processes in resource-constrained settings, when officials are already burdened with numerous other human rights and gender assessment tools and processes in global health? And are risk assessments well integrated into processes of decision-making—or do they risk being check-the-box exercises sidelined from the faster pace of real-world digitization?

These questions would benefit from further discussion by UN and global health donors, in order to ensure that health officials have operational approaches that are effective in mitigating human rights risks of digital health for young women and marginalized groups.

A second set of questions that arise from the UNDP and WHO guidelines has to do with pinpointing accountability for adverse impacts in digital health: it is not always clear where responsibility lies, whether with the designer of a digital intervention, the company that produces it, or the health agency that applies it. For example, if an AI-enabled tool is able to predict likelihood of an illness, harm could be caused at various points on a chain of decision-making: by assumptions and data sources that design and train the algorithm incorrectly, from decisions made by healthcare workers based on flawed predictions, or from data breaches that expose individuals to stigma, discrimination, or intrusive marketing. UNDP does not wrestle with this question in its guidance. WHO recommends applying a "human warranty" in which a human approves a decision at key moments along this chain of decisions, but admits that this approach is still vague, and law has yet to pinpoint accountability in many countries (WHO 2021: 28).

A third challenge arising from the two guidance documents has to do with the growing split between human rights and ethics in governance of digital health: as noted above, UNDP favors human rights, while WHO favors ethics. As Khosla and Gruskin (2021) observe, ethics and human rights are often viewed as competing rather than complementary in global health governance, and "depending on the champion, one or the other [is] often considered irrelevant".

There are now dozens of sets of principles developed for governance of digital technologies and AI. They include the *Principles for Digital Development* https://digitalprinciples.org, developed collaboratively by international development agencies in 2015, as well as the *Digital Investment Principles*, a set of principles endorsed by the Gates Foundation, Global Fund, GAVI, Unitaid, USAID, and more. One excellent example is the policy on biometrics passed by the International Committee of the Red Cross, which sets out legitimate uses of biometric data, commits to impact assessments for data processing, and establishes constraints on partnerships with the private sector.

One review of 36 sets of ethical principles documents for governance of AI shared key themes, but only five documents explicitly used a human rights framework. As former UN Special Rapporteur on Extreme Poverty, Philip Alston, argues, such ethical principles approaches to digital governance risks turning human rights into individual entitlements that could be granted or withheld at will, rather than state obligations that must be upheld.

Rather than developing separate approaches, as the field continues to develop, it would be ideal if global health organizations could align on one shared set of policies and risk assessment tools, and also advance analysis of accountability in digital health. This will support continued jurisprudence and governance development at the country level, and also avoid a situation in which each country cherry-picks the principles it finds easiest to adopt, and ignores the challenging ones.

To date, none of the mechanisms reviewed for this paper have addressed all of the specific questions relevant to human rights and digital health for women and marginalized groups discussed in the beginning of this paper. As the issues continue to rise on the agenda of regional mechanisms, the Digital Health and Rights Project may consider drawing on its research to brief EU and AU officials on the research results, perhaps in collaboration with other human rights organizations that have sustained engagement in these spaces.

4.4 What Role for Civil Society and Community Participation?

As the above discussion has indicated, norms and standards for governance of digital health are at an early stage of development, with much work to be done to further elucidate the protections and practices needed to protect rights and maximize the potential benefits. The Digital Health and

Rights Project will seek to contribute to these discussions by further elucidating principles and good practices in community engagement in digital health governance.

To begin, we will draw on the human right to participation as it has been developed in the HIV response, including the normative standards countries must uphold to protect civil and political rights. The right to participation relies on numerous rights in the *International Covenant on Civil and Political Rights*, including the rights to freedom of expression; freedom of assembly; freedom of association; the right to seek, receive and impart information; and the right to education (including human rights education). To ensure non-discrimination and equality, participatory processes must also meet standards of availability, accessibility, adaptability, and acceptability (Fjeld et. al. 2020). Similarly, human rights principles of transparency (and relatedly, the explainability of algorithms) are important prerequisites to fulfill the right to participation.

The right to public participation in development, including in health, is also underscored in normative guidance and soft law, as well as in norms guiding development cooperation: for instance, it is affirmed as part of countries' commitment to realizing the Sustainable Development Goals. The UN Common Understanding on a Human Rights-Based Approach notes that in development cooperation, "people are recognized as key actors in their own development, rather than passive recipients of commodities and services''. OHCHR's *Principles and Guidelines for a Human Rights Approach to Poverty Reduction Strategies* emphasizes that "country ownership should not be interpreted narrowly to mean ownership on the part of the Government alone. The strategy has to be owned by all stakeholders within the country, including the poor'' (OHCHR 2004: para. 63).

Within the HIV sector, there have been ongoing efforts to embed the Greater Participation of People with AIDS (GIPA) as articulated by UNAIDS (2007) into global health governance at national, regional, and global levels. The HIV sector has demonstrated the transformative impact that transnational advocacy led by those directly affected can have in promoting access to treatment in low and middle-income countries. Networks of people living with and affected by HIV, including women and key populations, lobbied for the establishment—and now occupy permanent seats on the governance boards—of the Global Fund, UNITAID and UNAIDS; and more recently, the civil society platform of the COVAX pillar of the Access to COVID Tools—Accelerator (ACT-A). While this participation is contested and there have been critiques of this inclusive role by some, numerous studies have suggested that this type of public participation is associated with positive health outcomes for maternal health and HIV prevention (Ferguson and Halliday 2013).

To what degree can community participation be embedded in governance of digital health? This is one area the Digital Health and Rights Project can explore in our research. Collectively, we have identified the following possibilities:

- In HIV, TB, and malaria planning, community representatives are expected to play active roles in the processes of developing these national strategic plans, as well as in developing prioritized funding requests for global health donors (Oberth 2015). Strategic planning about investments in digital technologies and AI in health should similarly be considered as part of national strategic planning processes for health that include diverse stakeholders.
- Existing civil society and community representation on the global boards and in national planning committees for the response to HIV, TB, and malaria should include discussion about opportunities and risks linked to digital health technologies.
- Young people should be consulted in impact assessments for digital health interventions, for instance those recommended by UNDP (2021) and WHO (2021) in their respective guidelines on digital technologies and AI for health.

These participatory roles are a first step, which could help to build more robust governance of digital health.

At the same time, simply including representation in these discussions may not go far enough, because they come late in the process of design and decision-making. A further step may require countering interpretive marginalization, by creating opportunities for diverse social and epistemic views to shape the design and implementation of new technologies. *The Principles for Digital Development* underscore that integrating user-centered design in the development of health technologies provides a crucial opportunity for developers to engage with the populations that will directly interact with the digital tool or system through means such as conversation, observation and co-creation mechanisms. This then enables designers to consider and incorporate feedback received into the design of the digital tool or system. Other approaches to ethical digital design propose to open these processes to interrogation in order to promote the accountable and transparent use of data (Bowles 2021).

Here our collaboration will need to connect with and learn from those with deeper experience in tech, noting that the availability of new platforms for mobilization and engagement have created space for new connections among researchers and rights advocates to connect, mobilize and engage to advocate for stronger regulation grounded in human rights (Niezen 2020). By linking digital rights activists with health rights activists, we may be able to communicate across the health/tech divides to find new ways to shape tech with community input.

As we reflect on how this can work in practice, we are ourselves exploring the benefits and real-world challenges of collaboration in knowledge production, through using a participatory action research (PAR) approach. Features of our approach to PAR include:

- co-design of research plans, protocols and tools
- intensive mentoring by senior researchers and managers to strengthen the capacity of junior researchers and staff in national organizations in low and middle-income countries, to conduct research and engage in public speaking
- collaborating on digital ethnography, focus group discussions, and key informant interviews across the three focus countries, with support among peer networks of PLHIV and human rights lawyers in Kenya, Ghana, and Vietnam
- training of young adult respondents in digital health and rights, training for UK youth activist networks, and linking youth activists with one another to support continued engagement
- respondent validation of the early analysis as it emerges, and
- collective reflection on the research results to develop policy recommendations.

In particular, we are inspired by and exploring two examples from our consortium in order to identify how they can inform our human rights analysis and refine our collective practices of community engagement:

- User-centered design to develop VOICE+, a project led by the Global Network of People Living with HIV (GNP+); the app connects networks of PLHIV for information-sharing and social accountability, and is being piloted and refined using an iterative approach.
- The anti-oppressive approach to collaboration and advocacy developed by STOPAIDS (2021), a reflexive approach which seeks to "encourage continuous self-reflection and consciously challenge the status quo and social norms" that create systemic injustice through a series of action-based questions that enable the questioner to identify challenges and levers for change. The questions are grounded in principles of listening, sharing space, accountability, effective and inclusive communication, adding value, encouraging marginalized stakeholders to participate, transparency, dignity, proactive challenging of oppression and inequality, and shifting power.

Drawing on these diverse conceptual tools, empirical evidence, communities of practice online, and our own practices of iteration and reflection, we aim to weave together new approaches and learning into ongoing research and analysis.

5 | CONCLUSIONS

In 2019, the UN Secretary General convened a global multi-stakeholder dialogue “on how we can work better together to realize the potential of digital technologies for advancing human well-being while mitigating the risks”. The resulting report included a recommendation to respect human rights (United Nations 2019: 29). What does this mean in practice? We aim to generate answers through ongoing research and reflection.

While thinking on how to apply human rights and ethical principles to digital health governance continues to evolve, the experience of the global HIV, TB and COVID-19 pandemics has clearly shown the need to consider how some groups of people face disproportionate risks of human rights violations, including due to widespread discrimination. To maximize the benefits and mitigate the risks of harm, sound digital health governance should be grounded in existing human rights norms, but also be continually informed by the robust and meaningful participation by affected communities in the decisions and designs that will shape their lives.

Regional human rights mechanisms are at an early stage of contending with the challenges of digital governance, and national courts are beginning to contribute to understanding how complex and contending rights should be balanced in practice. While UN agencies have begun to establish normative standards for governance of digital health and AI, they have not yet come together to clarify how these should be applied in practice. Twenty-first century technologies may require new thinking and practices that decentralize traditional systems of knowledge production, and develop new models of collaboration.

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