

# Guidance on the rights-based and ethical use of digital technologies in HIV and health programmes



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## Introduction

Unleashing the transformative power of science, technology and innovation is vital to achieving the 2030 Agenda for Sustainable Development, including the commitment to leave no one behind. Advances in digital technologies offer new means of addressing complex global challenges to unlock more equitable and sustainable development, be it is drone-supported climate solutions, user-friendly applications for vaccine cold chain management, digitization of health information systems, or blockchain for financial inclusion.

The United Nations – through the Secretary-General’s Strategy for New Technologies (2018), the High-level Panel for Digital Cooperation (2018–2019), and most recently, the Secretary-General’s Roadmap for Digital Cooperation (2020) – has acknowledged that digital technologies provide great opportunities to promote health and wellbeing. It has also recognized the challenges that they might pose to security, privacy, human rights, and the norms and standards of international law.<sup>1</sup> UNDP’s *Strategic Plan 2018–2021* and *Digital Strategy* highlight the importance of harnessing the positive potential of technologies to drive progress on sustainable development and the organizational commitment to “continually seek out and embrace existing and emerging digital technology in all aspects of its work to better serve its partners in their efforts to achieve the SDGs”.<sup>2</sup> *UNDP’s HIV, Health and Development Strategy 2016–2021: Connecting the Dots* highlights using digital technologies to increase access to HIV and health services as one of the promising opportunities for innovation and acceleration of progress towards the health-related Sustainable Development Goal (SDG) targets, and for building more resilient systems for health.<sup>3</sup>

COVID-19 has highlighted systemic weaknesses in health systems across the world and exposed deep-rooted inequalities across societies, with a disproportionate impact on vulnerable and marginalized groups. The pandemic has also demonstrated that health systems globally, whether robust and well-resourced, or weak and fragile, struggle with affordability, inequitable health care access, uneven outcomes and increasing demands for services.<sup>4</sup> The pandemic accelerated the use of digital technologies to support the public health response including for population surveillance, case identification, contact tracing, testing, the provision of health services and the implementation of quarantine measures.<sup>5</sup> Digital technologies facilitated pandemic strategies and responses in ways that would have been difficult to achieve manually.<sup>6</sup> Digital health technologies (i.e. ‘digital health’)<sup>7</sup> can help address health system challenges and achieve universal health coverage.

The World Health Organization (WHO) *Global Strategy on Digital Health 2020–2025* recognizes that digital technologies are an essential component and an enabler of sustainable health systems and universal health coverage.<sup>8</sup> Its vision of digital health technologies is to:

“improve health for everyone, everywhere by accelerating the development and adoption of appropriate, accessible, affordable, scalable and sustainable person centric digital health solutions to prevent, detect and respond to epidemics and pandemics, developing infrastructure and applications that enable countries to use health data to promote health and wellbeing.”<sup>9</sup>

As countries work towards achieving the SDG 3 – *Ensure healthy lives and promote well-being for all at all ages*, including the targets on ending the AIDS epidemic as a public health threat and achieving universal health coverage by 2030, digital technologies offer clear opportunities to improve service delivery and health systems. For instance, they can facilitate the provision of a more coordinated and higher quality care, increase access to specialized medical expertise, as well as support better patient engagement and access to quality health services at lower costs.<sup>10</sup> Nevertheless, the application of these technologies is most successful when informed by ethics and human rights, and nestled within broader, comprehensive approaches to addressing health outcomes. When there is the appropriate ethical, technical and legal infrastructure, including accountability mechanisms, that safeguard against rights violations, digital technologies can be invaluable in enabling HIV and health programming to become more people-centred, supporting individuals and systems to overcome barriers to access and realize the right to health for all.

The Global Commission on HIV and the Law noted that digital health technologies have the potential to support people living with HIV and its co-infections to reliably make more informed decisions with less stigma, and take control of their health care.<sup>11</sup> However, new and emerging digital technologies can also face challenges in realizing these opportunities while protecting human rights. The Commission cautioned that governments should establish legal protections to safeguard the privacy and confidentiality of users of digital health technologies, ensuring that online health-care records, electronic medical records and communications with health-care providers are protected. To guarantee that the most vulnerable are not excluded, it is necessary that strong measures be taken to protect their privacy when technology is used in HIV programmes.<sup>12</sup> Violations in privacy and confidentiality, particularly where groups are subject to punitive or criminal laws, may lead to human rights violations such as unjust detention, violence or death for people living with HIV and key populations, including sex workers, people who use drugs, lesbian, gay, bisexual, transgender and intersex (LGBTI) people, prisoners and people in closed settings, as well as other vulnerable populations such as migrants and women and girls.

Digital health technologies may also exacerbate health inequities. For example, the digital divide – i.e. the gap between demographics and regions that have access to modern information and communications technology, and those that have restricted access or do not access – still disadvantages millions of people. Additionally, electronic medical records and mHealth interventions (i.e. the use of mobile and wireless technologies to support the achievement of health objectives) can unintentionally reinforce or amplify legal, economic, social and cultural inequalities embedded in health systems based on citizenship, language, or income. Designing and implementing digital health technologies for HIV and health with attention to ethical principles and rights-based obligations help ensure that everyone, everywhere, has access to and benefits from health care enhanced by appropriate digital interventions.

Building on the work of the Global Commission on HIV and the Law, as well as the July 2019 UNDP Expert Consultation on *Digital Technologies and Data for HIV and Health: A Rights-*

*Based Approach*, and taking note of the new *Global AIDS Strategy 2021–2026: Ending Inequalities, Ending AIDS*,<sup>13</sup> this Guidance provides key ethical, human rights and technical considerations for countries looking to adopt digital technologies for health. It outlines key considerations from ethical, technical and social perspectives, and the human rights risks, norms and standards relevant to the use of digital technologies for HIV and health. It provides a practical checklist for assessing key ethical and rights considerations in adopting digital technologies; and finally, provides recommendations to various stakeholders.

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section 2

## Key ethical, technical and social considerations for the adoption of digital health technologies

The key step in considering the adoption of digital technologies for HIV and health should be to assess whether the digital technology is needed to resolve an issue or barrier within the HIV response or health system, and whether there is evidence of the effectiveness of the proposed technological solution. Digital health technologies work best when used as a tool within a broader system to facilitate more effective HIV and health responses. Moreover, digital interventions that are built on systems whose flaws have not yet been addressed can replicate inefficiencies, exacerbate inequity, and hinder effective responses.

This section covers critical ethical, technical and social factors that countries should consider when thinking about adopting digital technologies for HIV and other health programmes. It starts with the ethical foundations and then presents other key considerations such as technical components (health technology assessments, incentivization of interoperability) and the social component of building trust.

### 2.1

One strategy for integrating ethical, technical and social considerations is to include them in national digital health strategies together with digital literacy and workforce training, and to adopt a holistic approach to advancing accountability and justice via digital health technologies. Addressing these elements is critical to both mitigate risks of digital health interventions and to ensure their efficiency, safety and uptake.

### Ethics and the use of digital technologies

The development, adoption and implementation of digital technologies for HIV and health should adhere to ethical standards. Various groups, such as the Institute of Electrical and Electronics Engineers, the World Economic Forum and the European Commission's High-Level Expert Group on Artificial Intelligence, have developed resources related to ethics and digital technologies.<sup>14</sup> Based on these resources, as well as on established principles in bioethics and HIV responses, key ethical considerations for digital health include:

- **Beneficence and well-being** – Digital health technologies should 'do no harm', and include an obligation to be aware of, and mitigate, harms that may occur. In addition to minimizing harmful effects, technologies should also maximize the benefits for humanity.<sup>15</sup> Benefiting human well-being must be a central tenant of digital health technologies.



- **Autonomy, informed consent, and privacy** – All individuals should be recognized as having agency over themselves and their personal information. This protection not only applies to the data collected from specific technologies, but also to data exchange mechanisms between various technologies. When personal information and/or data are collected with full informed consent, there should be safeguards to protect their integrity and security, including ‘purpose limitation’ (see Section 3 on ‘rights-based legal and regulatory framework’ below).
- **Participation and inclusion** – Technologies should be co-designed with people whose personal information and rights will be impacted by them (participatory design). Moreover, they should be involved in the implementation, monitoring and evaluation of digital health tools. Technologies should be inclusive of all within society, including the most marginalized and those most left behind.
- **Transparency** – Digital health technologies should be developed, adopted and implemented in an open and accessible manner that allows for public feedback, consultation and monitoring. This entails ensuring algorithmic transparency – i.e. the principle that factors that influence the decisions made by algorithms should be visible to the people who use, regulate and are affected by the systems that use these algorithms.
- **Non-discrimination and equity** – Digital health technologies should not deliberately or unintentionally discriminate against individuals. Moreover, to ensure equity in implementation, these technologies should account for the needs of vulnerable and marginalized groups, including women, children, racial and ethnic minorities, migrants, people living with HIV and other key populations. Effective, non-digital options should also be available and accessible to all.
- **Accountability** – Remedies should be provided for rights violations related to digital health technologies, and accountability and oversight mechanisms put in place. To this end, a variety of approaches can be taken, including fostering enabling legal and regulatory environments (i.e. litigation, complaints/user feedback mechanisms, etc.).

## 2.2 Technical considerations

Adopting and implementing digital technologies for HIV and health must consider user accessibility and their availability. This includes considering infrastructure needs, such as availability and strength of internet access and cell phone coverage. Decision makers should also consider the availability, accessibility and cost of the hardware (e.g. computer, cell phone) and software needed to use specific digital technologies. To ensure equity in the use of digital technologies, these considerations should emphasize their availability and accessibility for marginalized populations, including persons of low socio-economic status, and account for gender, race and other statuses, such as membership of a key population affected by HIV. Since new digital technologies are tools that should be used to support health systems and health outcomes, it is critical for countries to provide support services to facilitate their adoption where the infrastructure permits. Countries should also provide effective, non-digital options for end users who may otherwise be unable to access or use digital technologies.

### 2.2.1 Health technology assessments

The regulation of digital technologies is complex given the rapid pace of innovation. A health technology assessment (HTA) is a specific tool that may support the regulation of digital technologies for HIV and health. An HTA is a multi-disciplinary process that evaluates the “value of health technology at different points in its lifecycle”, including the technology’s properties, effects and impacts.<sup>16</sup> It aims to inform policymakers and influence decision-making in health care, with a focus on how best to allocate funding for health programmes and technologies. Components of an HTA include validation of technical aspects (i.e. accuracy of the product or system), clinical considerations (i.e. contribution towards improving or maintaining a specific health condition) and systems compatibility (i.e. connection and/or integration into health service provision and health systems, including medical records).<sup>17</sup> HTAs can be applied to different types of interventions, such as piloting tests, medicines, vaccines, procedures and programmes.

Applying HTAs to digital technologies provides an opportunity for governments to assess their ethical and human rights risks, including those related to equity and community acceptability. Also, HTAs may be applied to digital health interventions that involve the use of protected, personal health information or other criteria that raises human rights risks. However, there are challenges in HTAs as digital health technologies evolve rapidly. Furthermore, the technology sector’s ethos of ‘moving fast and breaking things’ is in contrast with the conventional process of health technology development and testing for patient safety and clinical efficiency, which upholds a ‘do no harm’ approach.<sup>18</sup>

To better tailor HTAs to digital health technologies with a focus on ensuring equity in availability and access, there are several key considerations. In addition to assessing the traditional technical, clinical and systems elements, integrating a strong focus on usability and human-centred design is critical. Digital technologies should be co-designed with end users and people whose personal information and rights will be impacted by them (i.e. healthcare providers, systems administrators, patients, communities). There should be subsequent, effective mechanisms for feedback and iteration; this is line with a cornerstone of product design, that the needs of the affected communities must be met. These mechanisms also facilitate uptake and effectiveness of digital technologies, and fulfil the key ethical and human rights principle of meaningful participation and engagement. HTAs should also assess the risks for bias or discrimination as a result of access to and use of the digital health intervention. This includes reviewing a digital technology’s accessibility and availability for all users, including those left furthest behind.

### 2.2.2 Incentivizing interoperability

Interoperability is the “ability of a system or product to transfer meaning of information within and between systems or products without special effort on the part of the user”.<sup>19</sup> This data sharing can apply across organizations as well as geographic boundaries. To achieve interoperability, there must be industry-wide standards that are adopted by all relevant entities that need to share information. Within the context of health systems, interoperability is important because sharing information about the health of patients and populations in

a seamless, timely manner can improve health outcomes. Importantly, when implemented with appropriate security measures, interoperability ensures effective data portability, which allows users to transfer their data from one system to another. The standards and systems for interoperability should include safeguards that protect the autonomy and privacy of users, with their central tenants focused on efficiency and effectiveness, as well as individual and population well-being. Interoperability must also have strict limitations to protect against ‘function creep’ – i.e. the use of collected data for purposes beyond its original intent. This is especially important in a context where information may be collected on criminalized or highly stigmatized populations.

Interoperability, while desirable within the HIV response and health-care sector, may require some incentivization. Digital technology developers and health-care entities may have economic incentives to make data sharing more difficult or expensive. Other challenges include lack of coordination among various entities within the health sector, as well as the fact that different institutions have differing policies related to data privacy and security.<sup>20</sup> To encourage interoperability, some countries have established incentivization programmes that provide funding for entities that adopt such technologies. These initiatives could also be offered to promote interoperability of systems that encompass strong privacy and data protections in order to address ethics and human rights considerations.

### 2.3 Social considerations – building trust

A core component of successful HIV responses, trust is also a key element in the adoption and success of digital technologies for health. Without trust, the implementation and uptake of digital health will be weak, even if all other aspects of infrastructure, as well as legal and regulatory frameworks, are effective. Trust must be built for all types of relationships related to digital health – between patients and health-care providers; within the health sector institutions; between the State and its residents; and between a State, its residents and the private sector. Strategies to foster trust that will enable the adoption and use of digital health technologies include:<sup>21</sup>

- being consultative and transparent in decision-making related to governance and management of digital technologies – this includes being transparent about and accountable for the factors that influence algorithmic decisions;
- establishing impartial, effective accountability and oversight mechanisms for breaches of data privacy and other rights violations;
- co-designing digital technologies and systems with affected communities, and creating monitoring and evaluation systems that allow the technologies to adapt based on feedback, where possible;
- investing in creating opportunities for digital rights literacy for communities and individuals to understand their rights and take ownership of their data, including the right to withdraw their data from use and to data portability;
- creating spaces for dialogue between various key stakeholders, such as the State, the private sector, civil society and communities.

## 2.4 Integrating ethical, technical and social considerations into the adoption and use of digital interventions for HIV and health

### 2.4.1 National digital health strategies

One way to avoid the ad hoc development of digital health technologies is the adoption of a national digital health strategy. Digital health strategies can facilitate coordination, set standards for interoperability, and establish policies related to digital health.<sup>22</sup> A country-wide strategy is also helpful for identifying gaps and opportunities where digital technologies can be best leveraged to improve health outcomes. The 2019 report of the Global Digital Health Index (GDHI) indicates that, out of the 22 current GDHI countries, Bangladesh, Jordan, Malaysia, Portugal, Thailand and the Philippines have the most advanced processes, policies and practices for digital health.<sup>23</sup>

One of the strategic objectives of the new WHO Global Strategy on Digital Health 2020–2025 aims to “stimulate and support every country to own, adapt and strengthen its strategy on digital health”.<sup>24</sup> There are some key characteristics for effective national digital health strategies. They should be developed in a consultative and transparent manner that accounts for the needs of vulnerable and marginalized communities and those living in urban, rural, as well as crisis and conflict settings. They should also have political support from a variety of different entities, including the government sectors that deal with health, communications, economics and data protection, human rights, and corruption, civil society organizations, communities and the private sector.<sup>25</sup> National digital health strategies should be coordinated and coherent with other relevant policies, including broader national digital transformation strategies. They should undergo periodic reviews to ensure relevance and recognize the rapid evolution of digital health technologies.

### 2.4.2 Digital literacy

For national digital health strategies to succeed, individuals and health professionals must be digitally literate and aware of the human rights protections relevant to digital health. Accordingly, the WHO *Global Strategy on Digital Health, 2020–2025* recognizes that advancing digital literacy, including through investments in the education, training and continued professional development of the health workforce, is critically important.<sup>26,27</sup> A global framework for measuring digital literacy is still underway. However, the challenge of digital literacy is particularly acute in low- and middle-income countries given the global disparities between developed and developing countries in access to computing and information resources including the Internet and the opportunities derived from this access.<sup>28</sup> For example, most of the countries participating in the GDHI provide weak pre- and in-service training for health professionals: 20 of the 22 countries either do not provide digital health pre-service training to health-care personnel or only do so for less than 25 percent of their workforce.<sup>29</sup> Limited efforts have been made to engage HIV or tuberculosis (TB) key and vulnerable populations, who may have frequent contact with the health sector and experience stigma and discrimination,<sup>30</sup> in digital health literacy initiatives.

### 2.4.3 Biometric and digital identify

For people without an officially recognized legal identity (ID) document, accessing basic services, including HIV and health service, can be a major barrier.<sup>31</sup> Digital ID systems with unique biometric features are mediating this problem, and there has been an accelerated adoption of digital ID systems, especially in low- and middle-income countries.<sup>32</sup> While the goal of establishing national digital ID systems as the basis of public service delivery presents opportunities for improving access to service and reducing corruption and wastage, they also pose the risk of excluding already marginalized populations, such as people living with HIV and key populations in criminalized settings, if proper safeguards are not in place to mitigate these risks.<sup>33</sup>

### 2.4.4 Advancing accountability and justice

Within national digital health strategies, countries should consider how digital interventions can advance broader efforts to promote accountability and justice. For example, within the HIV response, eHealth apps may be used by community members to monitor medication stockouts<sup>34</sup> (e.g. antiretroviral therapy in the HIV response) or to address discriminatory treatment in health-care facilities.<sup>35</sup> They may also facilitate reports of abusive law enforcement practices against vulnerable and key populations. Regarding equity considerations for data and digital health interventions more broadly, governments should consider representational visibility of data, i.e. considering whose data are being collected (there must be a balance to ensure that the most marginalized are visible for critical services, but not targeted for discriminatory purposes), and how best to promote transparency and equity related to data and technological innovations (e.g. open source software and open data sets).

### 2.4.5 Tackling corruption in the health sector

Each year an estimated US\$7.5 trillion is spent worldwide on providing health services, yet as much as 6%, or approximately \$455 billion, is lost to corruption.<sup>36</sup> Corruption in the health sector undermines public trust, wastes resources, violates human rights, and negatively impacts health outcomes for the most vulnerable. Digital technology can serve as a powerful contributor to anti-corruption, transparency and accountability efforts, and can be leveraged to detect and deter corruption while promoting citizen trust and engagement. For instance, digital initiatives have included: open-contracting policies to correct information asymmetries among the multitude of actors involved in procurement processes;<sup>37</sup> electronic logistics management information system (eLMIS) that use smartphone and cloud-based technology to capture real-time data across the entire vaccine cold chain;<sup>38</sup> and digital payment platforms to reduce the risk of fraud and verify cash transfers.<sup>39</sup>

## The rights-based legal and regulatory framework

From their design to their adoption and implementation, digital technologies for HIV and health can raise human rights concerns. This section provides a short overview of some key human rights risks that have been identified in digital technologies for HIV and health. The section then discusses human rights obligations of States and private actors that arise from global, regional and national agreements, and norms and standards.

### 3.1 Human rights risks and digital technologies

Despite the opportunities that digital technologies can bring by creating more effective and efficient HIV and health responses, their adoption should take into account key human rights considerations, such as those related to privacy and non-discrimination. This is especially relevant in the HIV response, given the disproportionate impact of the disease on marginalized, stigmatized and criminalized communities.<sup>40</sup> Although there are many specific causes of human rights risks related to the use of digital technologies, focus will be placed here on the following three common causes – data breach, bias and function creep.

#### 3.1.1 Data breach

A ‘data breach’ refers to any breach of security that leads to the “accidental or unlawful destruction, loss, alteration, unauthorised disclosure of, or access to, personal data”.<sup>41</sup> Data breaches are common in the health sector and have a variety of causes – from malware and hacks, to accidental or purposeful disclosure of personal health information by health-care employees.<sup>42</sup> There have been several recorded incidents of protected health information data breaches globally, including the leak of the personal information of about 14,000 people living with HIV in one particular incident.<sup>43</sup> Data breaches violate an individual’s right to privacy and erode trust in the health-care system. As technology evolves and health systems become more complex, the likelihood of data breach occurrences increase. Health systems should invest in information security and keep up to date on the latest in data protection to prevent breaches.

#### 3.1.2 Bias

Discrimination resulting from biases present in algorithms of AI and other automated processes has been repeatedly documented across a wide range of applications. This phenomenon, also known as ‘algorithmic bias’, can amplify discrimination in criminal justice proceedings and predictive policing, facilitate discriminatory hiring decisions, and produce targeted online marketing campaigns with discriminatory effects.<sup>44</sup> Within health care, studies examining applications of AI have demonstrated that algorithms do not provide equally accurate predictions of health outcomes across race, gender, or socio-economic status. For example, one study that analysed AI predictions for intensive care unit mortality found that use of AI resulted in a higher error rate for female patients than for males.<sup>45</sup> These biases are reflective of the underlying bias in data used for the development of AI and machine learning applications, and the limited comprehensiveness of relevant variables in many existing datasets used to develop algorithms. This raises concerns over an individual’s right to non-discrimination. Additionally, certain types of algorithmic decisions

evade current non-discrimination laws,<sup>46</sup> leading to unfair differentiation that is technically legal (e.g. offering differing prices for the same product based on speed of internet access, etc.), but still counterproductive to health equity aims of digital technology application.

### 3.1.3 Function creep

'Function creep' refers to the "gradual widening of the use of a technology or system beyond the purpose for which it was originally intended, especially when this leads to potential invasion of privacy".<sup>47</sup> Concretely, there is function creep when data collected for a specific purpose (e.g. as personal history information for HIV testing or treatment) are used for another purpose (e.g. to check immigration status). Concerns over function creep are present in all forms of digital technology application for health (e.g. molecular surveillance), but especially in relation to biometrics. Potential risks of biometric data include abuse of data for different purposes, such as forensics or criminal proceedings.<sup>48</sup> Function creep can also lead to data breaches, particularly among marketable technologies for health. For example, wearables are often produced and managed by private companies with greater interest in collecting and monetizing personal information than in protecting it, which poses a significant threat to the data privacy of individuals. Government partnerships with private companies, including big technology companies, have also raised alarms related to the exploitation of data for surveillance as well as commercial purposes.<sup>49</sup>

Good practices for data privacy to prevent function creep centre on the principle of 'purpose limitation', i.e. data can only be collected and used for an explicit and legitimate purpose. If a new purpose arises, informed consent must again be solicited and given for the data to be used in such a manner (for more information, see 3.4 below for more on data privacy and security protection).

## 3.2 International human rights standards for States

Human rights obligations apply to States in digital environments in the same manner that they apply in offline environments. While there is no specific global human rights agreement for digital technologies, many existing human rights obligations apply. The most relevant state obligations for the adoption of digital technologies for HIV and health are the rights to health, non-discrimination, benefits from scientific progress and privacy. Although States are primarily responsible for respecting, protecting and fulfilling human rights obligations, private companies that are domiciled or conduct business within a State's jurisdiction must also, at a minimum, respect human rights standards. Given that digital health technologies may be used across multiple countries and jurisdictions, international human rights law provides uniform standards for States' obligations, making it a strong foundation on which to build the governance framework for such technologies.

### 3.2.1 Right to health

The right to health is enshrined in various human rights treaties, including Article 12 of the International Covenant on Economic, Social and Cultural Rights.<sup>50</sup> The Committee on Economic, Social and Cultural Rights has noted that the right to health is interrelated and "indispensable for the exercise of other human rights. Every human being is entitled to the

enjoyment of the highest attainable standard of health conducive to living a life in dignity”.<sup>51</sup> The following four key elements comprise the right to health:

- Availability – Health facilities, goods and services must be available in adequate quantities within a country.
- Accessibility – Facilities, goods and services must be sufficiently accessible and provided in a non-discriminatory manner. ‘Accessibility’ refers to various form of access, including economic accessibility (affordability), physical accessibility (e.g. services are within reasonable travel distances and/or meet the needs of persons with disabilities) and information accessibility.
- Acceptability – Facilities, goods and services must be culturally appropriate, including for marginalized and vulnerable groups, and respect medical ethics, such as maintaining privacy and confidentiality.
- Quality – Facilities, goods and services must be of good quality, and based on scientific and medical evidence.<sup>52</sup>

Core obligations of the right to health include ensuring:

- access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups;
- access to the minimum essential food that is nutritionally adequate and safe to ensure freedom from hunger to everyone;
- access to basic shelter, housing and sanitation, and an adequate supply of safe and potable water;
- the provision of essential drugs, as defined under the WHO Action Programme on Essential Drugs;
- equitable distribution of all health facilities, goods and services;
- the adoption and implementation of a national public health strategy and plan of action, based on epidemiological evidence, which address the health concerns of the whole population.<sup>53</sup>

While the right to health is subject to progressive realization, there are immediate state obligations that must be met, including executing the right in a non-discriminatory manner and recognizing that the country has a “specific and continuing obligation to move as expeditiously and effectively as possible towards the full realization” of the right to health.”<sup>54</sup>

The adoption of digital technologies for HIV and health must, at a minimum, satisfy the four key elements of the right to health (availability, accessibility, acceptability and quality). These key elements have also been recognized as elements of the right to enjoy the benefit of scientific progress and are applicable to digital technologies.<sup>55</sup> Indeed, addressing availability and accessibility of digital technologies for HIV and health supports efforts to bridge the digital divide. These obligations require governments to ensure the availability and accessibility of digital infrastructure throughout the country, both in terms of hardware (e.g. computers, mobile phones, mobile phone towers, internet, and broadband accessibility) and software (e.g. applications). This also includes providing digital literacy training for all users, such as those in leadership, health care and communities.<sup>56</sup> Digital



technologies for HIV and health should be a step towards supporting countries to realize the right to health; hence, they must be reasonably accessible to all communities, especially those that are left furthest behind. Moreover, with respect to the right to health, acceptability of digital technologies entails not only ensuring the right to privacy and confidentiality, but also meeting the needs of different populations.<sup>57</sup> Finally, digital health technologies must be of quality; for example, those that attempt to replace in-person care should be held to the same norms and standards.

### 3.2.2 Right to non-discrimination

The right to non-discrimination is found throughout various global treaties, beginning with the International Covenant on Civil and Political Rights (ICCPR).<sup>58</sup> States must uphold the right to non-discrimination both as a right in itself and as a principle that is inherent in the realization of other rights (e.g. entitlement to equal treatment before an impartial tribunal). Human rights law defines discrimination as:

“[...] any distinction, exclusion, restriction or preference which is based on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status, and which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise by all persons, on an equal footing, of all rights and freedoms”.<sup>59</sup>

‘Other status’ has been interpreted under human rights law to include HIV and other health status, as well as sexual orientation and gender identity.<sup>60</sup> Importantly, the right to non-discrimination does not imply identical treatment for all – some instances may necessitate differential treatment to ensure that individuals are on equal footing. Differential treatment does not constitute discrimination where the criteria for such differentiation are “reasonable and objective and if the aim is to achieve a purpose which is legitimate” under human rights law.<sup>61</sup>

Emerging and new technologies raise two main categories of concerns related to non-discrimination. The first focuses on their access and availability, while the second focuses on implicit biases within them. Relying on digital technologies as a primary system or strategy within the health sector may impact access and availability, and inadvertently exacerbate inequalities, contributing to the digital divide. This may be due to a myriad of reasons including limited technical infrastructure (e.g. broadband access, satellite towers), lack of digital literacy, expense, and lack of access to digital hardware (e.g. mobile smart phones, computers).<sup>62</sup> Human rights and technologies experts recognize that the design of various digital technologies may include implicit and inadvertent biases. Engineers and software developers tend to be based primarily in the Global North, and to design technologies with limited engagement and inputs from diverse communities, such as those that are inclusive of race, gender and socio-economic backgrounds.<sup>63</sup>

To realize the right to non-discrimination in the context of digital technologies, States must proactively identify risks to non-discrimination in access and availability of technologies, and hold private businesses to account in identifying, mitigating and redressing discriminatory outcomes.<sup>64</sup> States should also ensure transparency and accountability related to the

development, adoption and implementation of digital technologies for health, as well as provide access to justice where the right to non-discrimination or other rights have been violated. Finally, there should be an effective, non-digital option that achieves the same goal for those who are unwilling or unable to use digital technologies.<sup>65</sup>

### 3.2.3 Right to enjoy the benefits from scientific progress

Article 15 of the International Covenant on Economic, Social and Cultural Rights enshrines the right to enjoy the benefits from scientific progress.<sup>66</sup> Like the right to health, States must take deliberate, concrete steps towards the realization of their obligations within a reasonable time frame. Moreover, States are:

“under an immediate obligation to eliminate all forms of discrimination against individuals and groups in their enjoyment of economic, social and cultural rights. This duty is of particular importance in relation to the right to participate in and to enjoy the benefits of scientific progress and its applications because deep inequalities persist in the enjoyment of this right”.<sup>67</sup>

The Committee on Economic, Social and Cultural Rights recognizes that the right to participate in and enjoy the benefits from scientific progress are fundamental to achieving the right to health. States have a duty to ensure availability and accessibility to “all the best available applications of scientific progress necessary to enjoy the highest attainable standard of health” on a non-discriminatory basis, with a focus on the most marginalized.<sup>68</sup> States are obliged to fulfil this duty to the maximum of their available resources. The Committee notes that States must balance the benefits and risks, specifically of emerging and new technologies. It underscores that new technologies should be developed and used within an inclusive, rights-based framework, highlighting the principles of transparency, non-discrimination, accountability, and respect for human dignity. The Committee also emphasizes the importance of developing laws that impose an obligation of human rights due diligence on private and other non-state actors. States must also regulate the control and ownership of data collected through new technologies to prevent misuse and exploitation, as well as ensure informed consent and privacy.<sup>69</sup>

### 3.2.4 Right to privacy

Article 17 of the ICCPR recognizes everyone’s right to be free from arbitrary or unlawful interference with their privacy.<sup>70</sup> This requires States to adopt laws, policies and practices that realize this right. Any lawful interference with this right must be precisely outlined in relevant legislation.<sup>71</sup> Moreover, States must regulate the collection and storage of personal information – these measures must be effective to prevent unauthorized disclosure or use of personal information.<sup>72</sup> Such information can never be used for any purposes that are incompatible with the aims of the ICCPR. In addition, individuals have the right to know what personal data are stored in databases and the purposes of such storage. They also have the right to request rectification or elimination of files that contain incorrect personal information or “have been collected or processed contrary to the provisions of the law”.<sup>73</sup> Choice of technology is an important factor in realizing the right to privacy – digital health technologies should build on and utilize platforms and processes that minimize privacy

risks, for example, using blockchain technology or exploring Bluetooth-based apps as a less-intrusive alternative to GPS tracking for contact tracing. Governments should also be aware of the privacy and security concerns that are not only related to a digital technology, but also to any data exchange mechanisms that they may use. For further elaboration on the right to privacy in the context of digital technologies, see the section 3.4 below on legal principles from regional and United Nations agreements.

### 3.2.5 The role of courts in upholding human rights in the digital age

Courts have historically played a key role in protecting human rights, including the right to health. Within the HIV response, judicial decisions have advanced a range of rights and freedoms, notably access to antiretroviral treatment as part of the right to health.<sup>74</sup> It is important to note that the obligations of States provided in international human rights treaties apply online as well as offline, which include respect for human rights and fundamental freedoms in the use of information and communication technologies.<sup>75</sup> These obligations must inform actions and policies relating to digital cooperation and digital technology. For the use of digital technologies, judiciaries around the world have led the way in protecting rights. Court decisions from India, Jamaica and Mauritius have recognized the right to privacy, as well as the importance of data protection related to digital technologies.<sup>76</sup> In a similar vein, in January 2020, the Kenyan High Court held that the Government's proposed biometric identification system required stronger privacy and data protections before it could proceed. The Court prohibited the Government from collecting individuals' DNA and location data as part of this initiative.<sup>77</sup> Moreover, a court in the Netherlands noted concerns over algorithm-related discrimination, calling for the Government to ensure transparent use of digital technologies and privacy safeguards.<sup>78</sup>

### 3.3 Human rights obligations of private businesses

The private sector plays a dominant role in the field of digital technologies and can inadvertently contribute to human rights infringements from their deployment. States have several obligations related to the action of business enterprises: they must protect against human rights abuses within their jurisdictions by third parties, including by private actors. This includes providing access to justice when business-related human rights violations arise. Governments must also set expectations that businesses domiciled in or operating within their jurisdiction must respect human rights, including by conducting human rights due diligence and taking into account issues related to gender and marginalization.

Although only States can be party to human rights treaties, there have been legal and normative developments that recognize that businesses and private companies must also comply with laws and respect human rights.<sup>79</sup> Respecting human rights requires private companies to:

- “ (i) avoid causing or contributing to adverse human rights impacts through their own activities, and address such impacts when they occur; and (ii) seek to prevent or mitigate adverse human rights impacts that are directly linked to their operations, products or services by their business relationships, even if they have not contributed to those impacts”.<sup>80</sup>

In alignment with these principles, companies should develop and enact human rights policy commitments and conduct human rights due diligence. This due diligence comprises ongoing processes that involve assessing human rights impacts, acting to prevent or mitigate impacts, tracking to see how concerns are addressed, and remedying any violations that it caused or to which it contributed.<sup>81</sup> Business enterprises should treat the obligation to respect human rights as a legal compliance issue in all jurisdictions in which they operate or are domiciled.

### 3.4 Legal principles from regional and United Nations agreements on data privacy and security

While there is no global treaty on data security and protection, there are several regional agreements and principles that set standards on these issues, which include the African Union Convention on Cyber Security and Personal Data Protection,<sup>82</sup> the Asia-Pacific Economic Cooperation (APEC) Privacy Framework,<sup>83</sup> the European Union's General Data Protection Regulation<sup>84</sup> (EU GDPR) and the Standards for Personal Data Protection for Ibero-American States.<sup>85</sup> The Council of Europe (CoE) also has the Modernised Convention for the Protection of Individuals with Regard to the Processing of Personal Data (Convention 108+), which is open for accession by non-member States.<sup>86</sup> Moreover, the United Nations system has also developed strong ethical principles on data security and privacy that aligns with regional standards.<sup>87</sup> The following legal principles are drawn from these standards.

#### 3.4.1 Rights of the data subject

Data privacy and security agreements enshrine a set of rights for the individual whose data are being collected (i.e. the 'data subject'),<sup>88</sup> including:

- the right to be informed about where data are and are not collected;
- the right to access stored data;
- the right to rectification;
- the right to erasure (i.e. the 'right to be forgotten');
- the right to restriction of processing;
- the right to be notified of rectification or erasure or restriction of processing;
- the right to data portability (i.e. an individual's right to request and receive personal data provided to one data controller in a structured, commonly used and machine-readable format or to have it transmitted directly to another data controller);
- the right to object;
- the right related to automated decision-making and profiling.

#### 3.4.2 Data collection and processing

Data must be collected and processed in a manner that:

- fulfils the requirements of lawfulness, fairness and transparency to the data subject;
- aligns with a legitimate purpose that is clearly specified and agreed to by the data subject (i.e. purpose limitation);
- is the minimum necessary for the legitimate purpose (i.e. data minimization);
- for personal and identifiable data, are only stored for as long as necessary for the specified, legitimate purpose (i.e. storage limitation);

- ensures appropriate security, as well as data integrity and accuracy;
- ensures that the entity that controls the data demonstrates compliance with all principles of data processing (i.e. accountability of data controller).<sup>89</sup>

In addition, a data subject's informed consent to data collection and processing must be voluntarily given in an unambiguous agreement to a request that is presented in clear and plain language. The data subject has the right to withdraw consent at any time.<sup>90</sup>

### 3.4.3 Data security and confidentiality

- Entities that process data must implement safeguards to ensure data security,<sup>91</sup> including anonymization or pseudonymization (whichever is more appropriate for the data collected), as well as encryption of personal data.
- Entities must also ensure transparency in the processing of data so that the data subject can monitor data processing, and the data controller can create and improve security features.<sup>92</sup>
- Certain categories of sensitive data may only be processed where appropriate legal safeguards are met, most notably those that mitigate risks to the rights and fundamental freedoms of data subjects. Such categories include genetic data, personal data related to criminal offences, unique identifying biometric data, and personal data that reveal a person's racial or ethnic origins, political opinion, religious and other beliefs, health and sexual life.<sup>93</sup>

### 3.5 Looking forward: Opportunities to advance human rights standards for digital health technologies

While there are several human rights obligations that States must fulfil in relation to digital technologies, there are also various opportunities to build on and develop new standards for digital health interventions. The most directly relevant is the Special Rapporteur on the Right to Privacy's *Recommendation on the Protection and Use of Health-related Data*.<sup>94</sup> The Recommendation covers key topics such as rights of the data subject, security and interoperability, transborder data flow, as well as considerations related to data and gender, indigenous populations and persons with disabilities. Moreover, the Special Rapporteur on Contemporary Forms of Racism is developing a report on new information technologies, non-discrimination and racial equality.<sup>95</sup> The United Nations' Chief Executive Board is also developing a recommendation on the ethics of artificial intelligence (AI).<sup>96</sup> These developments, together with the standards established by human rights law and the guidance from rights-based principles and experts,<sup>97</sup> will facilitate more just, ethical and rights-respecting uses of digital health interventions.

Digital technologies have the potential to reduce inequities and barriers to accessing quality HIV and other health-care services. They have the potential to decrease health-care costs, transform health systems to provide more accurate and responsive care, and break down siloes between sectors. However, these opportunities must be developed, implemented and monitored in a way that respects, protects and fulfils ethics and human rights. The adoption of digital health technologies in this manner will truly protect and empower individuals, thereby helping countries fulfil their commitment to leaving no one behind.

## Checklist for assessing key ethical and rights considerations in adopting digital technologies for HIV and health

Aligned with the recommendations for the use of digital technologies for HIV and health, below is a checklist to support countries in their decision-making on the adoption of digital health interventions. The checklist focuses on whether the adoption of the technology will help countries realize the right to health, and whether appropriate safeguards are in place to protect users.<sup>98</sup>

Checklist to support countries in their decision-making on the adoption of digital health interventions	
Key considerations	<input checked="" type="checkbox"/>
<b>Threshold questions</b>	Is this technology needed to address or resolve a critical issue or barrier within the HIV response or health system? Will it facilitate or streamline access and/or quality of facilities, goods and/or services (e.g. considerations of complementarity of systems, technology as a tool for good)? <input type="checkbox"/>
	Is there objective evidence on the clinical effectiveness of the proposed technological system or intervention for achieving the proposed HIV or health goal? <input type="checkbox"/>
	Is this technology reasonably accessible to the population that should benefit from its design and implementation (e.g. if the technology requires mobile smart phones, do most people have them)? <input type="checkbox"/>
	Has this technology been co-designed with users and/or has meaningful consultation with and input from communities been sought? <input type="checkbox"/>
<b>Availability</b>	Logistics support: Are there technological and other fundamental infrastructure in place to support the implementation and uptake of this technology to meet the HIV or health goal (e.g. access to internet and/or mobile phone coverage throughout the country, even in rural areas, etc.)? <input type="checkbox"/>
<b>Accessibility</b>	User access: Do end-users have the hardware (e.g. computers, mobile smart phones) and software necessary for accessing and using this technology? <input type="checkbox"/>
	Is the government able to provide access to hardware or software for users and/or areas where it is currently not available or accessible? <input type="checkbox"/>
	Will end-users incur any costs for using this technology, and if so, are they affordable and/or covered by insurance? <input type="checkbox"/>
	Is the technology accessible to specific requirements from people, such as persons with disabilities, the elderly and children? <input type="checkbox"/>
	Is the technology available to, and appropriate for, vulnerable communities, including but not limited to people in prisons and closed settings, people who are internally displaced and/or those in refugee or informal settlements? <input type="checkbox"/>

## Checklist ... continued

Key considerations



### Acceptability

Is the technology available in the necessary languages? Are they tailored to take into account user experience based on gender, sex, ethnicity, or other major factors (such as membership to a key population group)?



Is the technology culturally appropriate within various communities?



Is training or are resources for training available in plain language and accessible formats to support digital literacy for a specific technology among health-care professionals and end users?



Has the specific digital technology been tested, piloted, or implemented to achieve the expected HIV or health goal?



### Data privacy and security

(Are there laws and regulations in place that outline clear legal standards on data privacy and security?)

Data collection:

- Are there clear informed consent requirements for data collection? Consent should be freely given, specific, informed and unambiguous, and the request presented should be in clear and plain language, with the purpose explicitly specified.
- Do the regulations specifically outline legitimate and lawful purposes for data collection?!
- Are there data minimization requirements (i.e. collecting the minimum necessary for the legitimate purpose)?



Storage and authorized use:

- Are there requirements for the data collected to be kept accurate, and if necessary, up-to-date?
- Are there standards that data processing methods ensure appropriate security and data integrity, including anonymization, where relevant, and rigorous processes to ensure authentication for authorized users and encryption?
- Are there mandates that personal, identifiable data can only be stored as long as necessary for the specified purpose (e.g. limited retention)?



Are there heightened protections for the collection and storage of special categories of data, including genetic data, personal data related to criminal offences, unique identifying biometric data, as well as personal data that reveal a person's racial or ethnic origins, political opinion, religious and other beliefs, health and sexual life?



Rights of the data subject: Do the applicable laws and policies include the following rights for individuals whose data are collected?

- the right to be informed of the use of their collected data;
- the right to access stored data;
- the right to rectification;
- the right to erasure;
- the right to restriction of processing;
- the right to be notified of rectification or erasure, or restriction of processing;
- the right to data portability;
- the right to object;
- rights related to automated decision-making and profiling.



Checklist ... continued

Key considerations

**Health-related surveillance<sup>100</sup>**  
(including contact tracing)

Are the proposed surveillance measures lawful and for legitimate public health objectives?

Are the measures strictly necessary and proportionate to the health objectives?

Are there explicit measures in place to ensure transparency in the development and implementation of the technology, as well as the use of data collected (including any agreements with private actors)?

Does the surveillance technology involve the meaningful and active engagement of key stakeholders, including civil society and communities, in its development, implementation and monitoring?

Are there user notification requirements?

Are there legal and regulatory protections for data privacy and security (in collection, storage and use), including the above-mentioned data and privacy requirements?

Are there safeguards to mitigate risks of discrimination or other rights abuses for marginalized groups?

Is there access to redress and justice for users who may have their rights violated through the use of the technology?

Is there an institution or entity that can provide public oversight, review and accountability on the use of the technology?

If the technology is for a specific, time-limited purpose (i.e. COVID-19 or any outbreaks), is its use time-bound?

**Non-discrimination**

Can pre-existing laws related to non-discrimination be applied to the impact and uptake of digital technologies?

How well are private companies regulated in terms of legal compliance regarding human rights issues? Are there mandatory provisions for human rights due diligence?

**Accountability and access to justice**

Are private actors required to have policy commitments to human rights and to conduct human rights due diligence in order to be legally compliant with the business regulations within the country?

Do individual and entities have the rights to bring cases related to potential discrimination as a result of digital technologies before courts (i.e. are technology-related discrimination claims justiciable?)

Are there other mechanisms and or interventions available to support access to justice for technology-related human rights violations (e.g. impartial courts specializing in surveillance issues, training for judges and law enforcement on the use of digital technologies, etc.)?



## Recommendations for the ethical and rights-based adoption of digital technologies for HIV and health

The following recommendations emerge based on the ethical, technical, social and rights-based legal considerations of digital health technologies for HIV and health. These recommendations are for governments and other stakeholders, such as private sector companies and donor agencies.

### 5.1 Recommendations for governments

To ensure that the development and use of digital technologies for HIV and health are consistent with universal human rights obligations and ethical principles, governments should adopt the following:

#### 5.1.1 The right to health

Ensure that the use of digital technologies for HIV and health uphold – and are a step towards the progressive realization of – the right to health and the right to benefit from scientific progress. Specifically, uses of digital technologies for HIV and health must, at a minimum, advance equity within availability, accessibility, acceptability and quality.

#### 5.1.2 The right to non-discrimination

- a. Proactively identify and mitigate risks to non-discrimination in access and availability of technologies, as well as privacy and confidentiality. Where private actors are involved, hold businesses to account in identifying, mitigating and redressing discriminatory outcomes, as well as privacy and data security violations (human rights due diligence).
- b. Enact an effective, non-digital option that achieves the same HIV and/or other health goal for those who are unwilling or unable to use digital technologies.
- c. For accountability purposes, ensure that non-discrimination laws and policies can be applied to the development, implementation and use of digital technologies for HIV and health.

#### 5.1.3 The right to privacy

- a. Establish and implement laws, policies and regulations on informed consent for data collection and use of digital technologies for HIV and health.
- b. Update and/or enact privacy laws, policies and regulations to safeguard the integrity and security of personal information/data.
- c. Within privacy laws and regulations, recognize the rights of data subjects, including:
  - the right to be informed about where data are and are not collected;
  - the right to access stored data;
  - the right to rectification;
  - the right to erasure (i.e. the 'right to be forgotten');
  - the right to restriction of processing;
  - the right to be notified of rectification or erasure or restriction of processing;
  - the right to data portability;
  - the right to object;
  - rights related to automated decision-making and profiling.

- d. Guarantee heightened protections for special categories of data (e.g. genetic data, personal data related to criminal offences or racial or ethnic origin, and biometric data) with appropriate legal safeguards to mitigate risks to the rights and fundamental freedoms of data subjects.

#### 5.1.4 Access to justice

Ensure that there are legal, regulatory and other accountability mechanisms to facilitate access to justice and redress for violations of human rights as a result of the development, implementation or use of digital technologies for HIV and health.

#### 5.1.5 Cross-cutting human rights obligations

- a. Ensure that all digital technologies for HIV and health are aligned with ethical considerations including the obligations of: beneficence; lawfulness; autonomy, consent, and privacy; participation and inclusion; transparency; non-discrimination and equity; and accountability.
- b. Ensure meaningful participation of end users and affected communities in the design, implementation and monitoring of digital technologies for HIV and other health services.

#### 5.1.6 Country strategies that support adherence to human rights and ethical obligations:

- a. Conduct rigorous baseline assessments of the HIV or health needs in partnership with the communities who are targeted benefit from the technology, assessing the challenges and identifying potential, effective interventions, and then making a decision about whether the best intervention is based on digital technology, the improvement of analogue systems, or a combination of both.
- b. Ensure that there are robust, principles-based regulations, with accessible accountability mechanisms that digital health technologies must comply with, including HTAs tailored to review the technical, clinical, systems and ethical aspects of digital interventions.
- c. Develop, implement and institutionalize digital literacy training for health-care professionals, end users/communities and other relevant stakeholders to facilitate access and uptake of digital technologies.
- d. Maximize interoperability of digital health technologies and systems to facilitate more effective and efficient HIV and other health service access and provision. However, safeguards must be enacted to protect personal information from being modified or accessed beyond the specified health purposes, especially for criminalized or highly stigmatized groups.
- e. Enact and periodically update a national digital health strategy that governs a country's approach to the adoption and use of digital technologies for HIV and health. The development of the strategy should be a consultative process that includes meaningful participation of relevant stakeholders and communities.

#### 5.2 Recommendations for the private sector and technology companies

Ensure that the development and use of digital technologies for HIV and health are consistent with universal human rights obligations and ethical principles, as follows:

- a. In line with the Guiding Principles on Business and Human Rights, prevent or mitigate adverse human rights impacts that are directly linked to their operations, products, or services, even if they have not contributed to these impacts.
- b. Develop and enact human rights policy commitments and conduct human rights due diligence. This due diligence comprises ongoing processes that involve assessing human rights impacts, acting to prevent or mitigate impacts, tracking to see how concerns are addressed, and remedying any violations caused by digital technologies or to which they may have contributed.
- c. Ensure alignment with ethical standards related to the development, implementation, monitoring and overall use of digital technologies for HIV and other health issues.
- d. Establish and implement clear accountability systems for digital technologies that violate human rights.

### **5.3 Recommendations to donor agencies**

To ensure that the development and use of digital technologies for HIV and health are consistent with universal human rights obligations and ethical principles, donors should adopt the following:

- a. Before funding or advocating for a digital health technology-focused project, conduct due diligence in assessing and understanding the gaps within a health system, which interventions may improve or address them, and how and if digital technologies may be used to support an effective intervention.
- b. Ensure that any digital technologies supported within projects or grants align with human rights and ethics principles, and that these interventions advance core elements of the right to health, including availability, accessibility, acceptability and quality. Technologies must also store data in a manner that safeguards privacy, confidentiality and security.
- c. Ensure that partnerships with the private sector and technology companies are thoroughly vetted so that they proceed in a manner that best protects and advances human rights, including the rights to health and non-discrimination.

## Annex: Overview of common digital technologies

Digital technologies are applied in numerous ways to support and enhance HIV and health programmes worldwide. This section highlights some examples of how they are currently used to support HIV interventions and health systems more generally.

Digital health interventions can be broadly categorized according to those that primarily target (i) individuals, (ii) health-care providers, or (iii) health systems management; as well as those that are (iv) cross-cutting and used in health research.<sup>101</sup> This section summarizes some common digital technologies currently used in HIV and other health responses, and highlights ethical and human rights concerns specific to individual technologies. However, since many digital health interventions share common concerns over data integrity, privacy and confidentiality, among other rights-related concerns, these cross-cutting risks are presented and addressed in section 4 as a part of a broader discussion of rights-based legal and regulatory frameworks.

### 1 Individuals

A range of digital health technologies have been developed specifically targeting the needs of individuals. This section provides an overview of eHealth interventions (including mHealth), wearables and point-of-care diagnostics.

#### 1.1 eHealth technologies

The World Health Organization (WHO) defines electronic health (eHealth) as “the use of information and communication technologies for health”.<sup>102</sup> Although eHealth can be defined broadly enough to include many of the other interventions covered in this section, basic eHealth technologies encompass the use of mobile phones (also known as mHealth) and websites to deliver medical or public health information. These technologies aim to facilitate the work of health providers and/or provide information or reminders to individuals. These interventions are low-cost and low-touch (i.e. minimal effort required by humans), and allow for customization of health information. Examples include: the use of mobile phone-based initiatives to deliver targeted health messages to pregnant and postpartum women;<sup>103</sup> the use of messaging applications (e.g. WhatsApp, Telegram) and internet outreach to facilitate access to harm reduction information for people who use drugs;<sup>104</sup> and the use of social media to address HIV-related stigma, encourage HIV testing and treatment<sup>105,106</sup> and to disseminate verified information on COVID-19 and HIV to young people.<sup>107</sup>

#### 1.2 Wearables

Wearable technologies (or ‘wearables’) are electronic devices worn close to and/or on skin, designed to collect biometric health information (e.g. heart rate, glucose levels). Wearables, including smartwatches and fitness trackers, are increasing in popularity due to their ability to provide individuals with health information directly, without health providers as intermediaries. Cost and maintenance are unique barriers to widespread adoption of wearables, especially as concerns over obsolescence (i.e. the market-driven, artificially limited use of products) grow among consumers.<sup>108</sup>

### Using mobile phone-based SMS to support pre-exposure prophylaxis adherence in Thailand

From July 2015 to June 2020, the Thailand Ministry of Public Health and the Center for Disease Control (MoPH – CDC) partnered with Mahidol University, Johns Hopkins University and other organizations to track the uptake of pre-exposure prophylaxis (PrEP) with mobile phone-based SMS adherence support. The study focused on HIV-negative young men (aged 18–26 years) who have sex with men. Study participants were sent tailored SMS messages to encourage adherence to the PrEP regime, disseminate information on HIV testing and prevention, as well as provide feedback to researchers. The research aims to analyse medical and cost-effectiveness of encouraging PrEP uptake in key populations with mobile phone adherence support.

### Using social media to support HIV prevention for key populations

In Panama, UNDP and the Global Fund are working with partners to provide services to key populations, including Asociación de Hombre y Mujeres Nuevos de Panamá (AHMNP), Asociación Panameña de Persona Trans (APPT) and Asociación Viviendo Positivamente (AVP). Partners are utilizing digital communication platforms to minimize the impact of COVID-19 on HIV prevention services for key populations through their work with homosexual men and other men who have sex with men, transgender people and sex workers. Using social media platforms, including Instagram, Facebook, Twitter and WhatsApp, and various dating apps, partners are delivering preventive health messages. In addition, health promoters are establishing online conversations with those at risk and offering follow-up services in the form of local meetings where condom distributions and HIV testing can take place.

*Sources:* Adapted from “COPE4YMSM: Effectiveness and Cost-Effectiveness of a Combination HIV Preventive Intervention With and Without Daily Oral Truvada® PrEP among Young Men who have Sex with Men (YMSM) and Transgender Women (TGW) in Bangkok and Pattaya, Thailand”, Johns Hopkins University. Available from: [www.jhsph.edu/research/centers-and-institutes/center-for-public-health-and-human-rights/research/key-populations-program/current-projects/cope4ymsm-thai-ymsm-prevention-effectiveness-evaluation.html](http://www.jhsph.edu/research/centers-and-institutes/center-for-public-health-and-human-rights/research/key-populations-program/current-projects/cope4ymsm-thai-ymsm-prevention-effectiveness-evaluation.html). See also “Combating HIV Spread in Thailand One Text at a Time”. FrontlineSMS. Available from [www.frontlinesms.com/blog/2020/5/14/combating-hiv-spread-in-thailand-one-text-at-a-time](http://www.frontlinesms.com/blog/2020/5/14/combating-hiv-spread-in-thailand-one-text-at-a-time).

## 1.3 Point-of-care diagnostics

Point-of-care (PoC) diagnostics involve the use of technology to conduct biological tests for any disease or condition at the time and place of patient care instead of in a medical laboratory.<sup>109</sup> PoC diagnostics for HIV-related programmes is most notably applied in HIV rapid testing, which has the potential to address many barriers to accessing testing if scaled up and implemented systematically.<sup>110</sup> Another area where PoC diagnostics hold promise is for tuberculosis (TB) rapid testing and increasing access to treatment.<sup>111</sup>

The benefits of PoC diagnostics include: increased access to testing; improved diagnostic capabilities (both in accuracy and ability to detect diseases at earlier stages); faster decision-making (through the ability to diagnose on the spot); and improved health outcomes through the earlier start of treatment. PoC diagnostics can also be used directly by individuals (e.g. home-based testing), which can make this technology more easily accessible than having to go to a health facility or clinic.

### Innovation expands HIV testing for key populations

In the Western Pacific, people are scattered across a multitude of remote and small islands, many of which have scant clinical health services. It is harder still for key populations affected by HIV because they face stigma and discrimination. Now, however, with support from UNDP and the Global Fund, a new diagnostic test for HIV and syphilis can be performed in remote settings without sophisticated equipment—just a simple finger-prick. Testing among key populations has increased 10 times since the roll-out began.

*Source:* Adapted from UNDP Pacific Office in Fiji brief: Pacific-wide rollout of rapid HIV and syphilis test to improve sexual and reproductive health services for the most vulnerable (23 October 2018). Available from [www.pacific.undp.org/content/pacific/en/home/presscenter/articles/2018/pacific-wide-rollout-of-rapid-hiv-and-syphilis-test.html](http://www.pacific.undp.org/content/pacific/en/home/presscenter/articles/2018/pacific-wide-rollout-of-rapid-hiv-and-syphilis-test.html)

## 2 Health-care providers

Digital health innovations are facilitating more effective and efficient, and higher quality health-care service provision. This section looks at the following interventions: electronic medical records (EMRs), health informatics and telemedicine.

### 2.1 Electronic medical records

EMRs use “digitized record[s] to capture and store health information on clients in order to follow-up on their health status and services received”.<sup>112</sup> EMR implementation aims to support providers by integrating decision-making tools (e.g. checklists prompting for clinical protocols, scheduling of timely follow-up visits) to guide providers while delivering care to patients. Within the context of HIV, EMRs have the potential to improve HIV service delivery and care; for instance, electronically shared medical records have been shown to support adherence to antiretroviral treatment.<sup>113</sup> The benefits of widespread EMR use include the minimization of common human errors, improved accuracy of patient care records, and enhancement of the health system’s abilities to plan for the care of populations.<sup>114</sup> EMRs also allow for the creation and use of digital portals where patients can independently and directly access their medical information. Protecting personal health information and data is a fundamental requirement of transitioning to, and maintaining, EMRs.

### Ensuring that pregnant women receive timely care

In India, UNDP is working with the Ministry of Health and Family Welfare in the State of Maharashtra to pilot an innovative digital solution to address critical service delivery gaps in maternal health care. The Antenatal, Neonatal, Child Health Systems and Logistics Tracking Tool (ANCHAL) initiative aims to support pregnant women through a smartphone app to reduce maternal morbidity. Frontline health workers, health facilities and government ambulance services are linked through a digital platform that can track women during their pregnancy, and ensure that they deliver at the most appropriately equipped facility, at the right time. The app is currently being tested in Pune District, among 3 800 frontline health workers.

## 2.2 Health informatics

Health informatics uses computer-based information systems in health care for five primary functions: (i) management of day-to-day needs of a health-care institution or system, such as planning and budgeting; (ii) clinical support, such as diagnosis and treatment; (iii) surveillance and epidemiological information on the patterns and trends of health conditions and programmes; (iv) the preparation of formal publications and other documentation; and (v) additional technical information for a technical task not directly related to clinical support, such as conducting laboratory tests.<sup>115</sup>

Health informatics are applied to support HIV-related programmes in several ways, including analysis of health system EMRs to identify opportunities to scale up HIV treatment, creation of health information exchanges (patient information sharing across different providers or systems), and evaluation of public health programmes to improve treatment adherence.<sup>116</sup> Benefits of health informatics approaches include the improved ability of health systems to track and manage patient care more efficiently and increased efficiency in data analysis and reporting.

### Digitalization of Zimbabwe's national health management information system

The United Nations Development Programme (UNDP), with the support of the Global Fund, the US Government and other partners, has been working with Zimbabwe's Ministry of Health and Child Care to digitize its national health management information systems (HMIS). This process has required laying the groundwork for a unified central digital management system across four systems: the electronic Patient Management Information System (ePMS); the Macro Database for site-level ePMS data; the District Health Information System 2 (DHIS-2), a national system that collects aggregate data; and the weekly Disease Surveillance System.

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Some of the key aspects of the project to date have been ensuring interoperability between systems, supporting enabling policy frameworks (including an information and communication technology [ICT] policy and an e-Health policy), facilitating strengthening of ICT infrastructure, and training of health-care professionals, data managers and policymakers in the HMIS systems. While the project is still ongoing, the work has already yielded positive results. For instance, improved interoperability between the ePMS and DHIS-2 has improved data accuracy and has enhanced the use and analysis of evidence at all levels of the health system. It has also improved coordination between various stakeholders who use the health data.

*Source: Adapted from UNDP, Zimbabwe Brief: UNDP and Global Fund support to strengthen the national health management information system (7 July 2020). Available from [www.zw.undp.org/content/zimbabwe/en/home/library/hiv\\_aids/undp-and-global-fund-support-to-strengthen-the-national-health-m.html](http://www.zw.undp.org/content/zimbabwe/en/home/library/hiv_aids/undp-and-global-fund-support-to-strengthen-the-national-health-m.html)*

## 2.3 Telemedicine

Telemedicine is broadly defined as:

“the delivery of health-care services, where distance is a critical factor, by all health-care professionals using information and communication technologies for the exchange of valid information for diagnosis, treatment and prevention of disease and injuries, research and evaluation, and for the continuing education of health-care providers, all in the interests of advancing the health of individuals and their communities”.<sup>117</sup>

Telemedicine can be and has been used in HIV-related programmes to support health-care workers in low-resource settings globally, consult on difficult HIV cases and deliver HIV case management remotely.<sup>118</sup> While the main benefit of telemedicine is overcoming geographical barriers to access, there are additional potential benefits for low-resource settings, such as connecting rural and remote sites to reverse the effects of ‘brain drain’ and the flight of human capital from these settings.

Restriction on movement during the COVID-19 pandemic resulted in an increased use of telemedicine in many countries, restricting in-person clinic appointments to medically necessary ones, and transitioning other appointments to newly scaled-up telemedicine services.<sup>119</sup> Telemedicine models were adopted for prescription re-fills,<sup>120</sup> and to access essential reproductive health-care services.<sup>121</sup> Some countries have also increased their administrative and/or financial support for telemedicine, for example: the Australian Government increased subsidies for telemedicine use; the Indonesian Government published a list of telemedicine providers on its COVID-19 website; and the Philippines announced a new national framework for telemedicine.<sup>122</sup>



### Telemedicine providing accessible health care in Libya

UNDP, in partnership with the Ministry of Health, the Government of Japan and a private sector start-up company, Speetar, launched the first telemedicine initiative in Libya. It addresses the shortage of doctors by connecting Libyans with physicians in diaspora communities who speak their language and understand the local context. It also reduces the burden of travel and mobility for people suffering from chronic diseases who require constant monitoring. This Telemedicine Initiative will engage with around 6,000 patients and 1,000 specialists, and will process 10,000 virtual consultations and E-prescriptions. The Libyan National Centre for Diseases Control also used the app to provide information and consultation on the COVID-19 pandemic.

*Sources: Adapted from UNDP (2020), UNDP, Japan, the startup Speetar, and the Ministry of Health launch the first telemedicine initiative in Libya (18 December 2020). Available from [www.ly.undp.org/content/libya/en/home/presscenter/pressreleases/UNDP-Japan-the-startup-Speetar-and-the-Ministry-of-Health-launch-the-first-Telemedicine-initiative-in-Libya.html](http://www.ly.undp.org/content/libya/en/home/presscenter/pressreleases/UNDP-Japan-the-startup-Speetar-and-the-Ministry-of-Health-launch-the-first-Telemedicine-initiative-in-Libya.html)*

## 3 Health systems management

Digital technologies have evolved to support improvements in various points in health systems management. Two examples highlighted in this section are digital identifications (IDs) and supply chain innovations.

### 3.1 Digital identifications

Digital IDs are electronic equivalents used to represent and prove a person's identity. Theoretically, digital IDs can improve access to high-quality health care and are used in numerous ways within the health sector, such as facilitating an individual's enrolment in insurance or social service programmes, and improving the ability to track health records across different providers.<sup>123</sup> A subset of digital IDs, biometrics, are biological markers of identity (e.g. from a blood sample, iris scan or fingerprint scan turned into a digital ID such as a number sequence). The benefits of biometric applications to HIV-related programmes include the reduction of patient misidentification inaccuracies and linking of biometrics to electronic health records to not only improve the quality of care delivered, but also to expand and improve the HIV surveillance capabilities of the system.<sup>124</sup> The use of biometrics, however, can pose significant rights-related risks, since it facilitates the identification of individuals, potentially exposing them to rights violations, especially when individuals belong to stigmatized, marginalized or criminalized groups.<sup>125</sup> Digital ID systems can also be built on analogue systems that are problematic in terms of access for specific communities, such as migrant or minority communities that already have difficulty accessing paperwork, among other shortcomings. Like other forms of digital technologies, the adoption of digital ID systems must be carefully considered to protect rights, as well as ensure equity in access and quality of care. To ensure this, risk assessments should be carried out at each stage of the planning and implementation of a digital ID system.

### 3.2 Supply chain innovations

Digital technologies can be used to support supply chain innovations in health systems; for example, effective digital interventions can improve the availability of critical health commodities such as medicines and vaccines. Innovations range from basic eHealth applications, such as the use of SMS and data dashboards in order to manage and report on supply levels, to the development of international surveillance tools in order to track entire supply chains and financing gaps of countries. WHO recommends the use of digital interventions to support supply chain innovations, noting that these technologies can improve allocation of health-care commodities and reduce wasted resources.<sup>126</sup> In turn, this leads to higher quality care and increased efficiency of service delivery.

#### Improving the immunization supply chain in India – the electronic Vaccine Intelligence Network

In India, UNDP, in partnership with the Ministry of Health and Family Welfare and GAVI, has supported the design and implementation of the electronic Vaccine Intelligence Network (eVIN) aiming to ensure equity in availability of immunizations. eVIN streamlines the vaccine flow network by relying on data-driven management of the immunization supply chain. The system digitalizes vaccine stocks at all 27,000 vaccine storage centres across all districts of 29 States and seven union territories of India, facilitating real-time monitoring of storage temperatures, building capacity of nearly 37,000 government personnel for vaccine and cold chain logistic management, and deploying vaccine and cold chain managers in every district for constant supportive supervision. Since its implementation, eVIN has reduced by over 80 percent the number of vaccine stock-outs and ensured improved availability of immunizations to its main beneficiaries: children and pregnant women. The eVIN system empowers its national and district-level managers as well as healthcare staff who can easily monitor and access the needed vaccines. Indonesia has also adopted the eVIN system, with strong results.

Sources: Ong, L. and Wee, M., *The Use of Digital Technology to Improve Vaccine Delivery in India and Indonesia*, Medium. (13 September 2020). Available from <https://medium.com/undp-in-asia-and-the-pacific/the-use-of-digital-technology-to-improve-vaccine-delivery-in-india-and-indonesia-cf024880fa0c>; UNDP, *Improving the efficiency of vaccinations systems in multiple States*. Available from [www.in.undp.org/content/india/en/home/projects/gavi1.html](http://www.in.undp.org/content/india/en/home/projects/gavi1.html)

## 4 Cross-cutting digital health technologies

‘Cross-cutting digital health technologies’ is a broad category that captures various forms of digital innovations that support research or technical building-blocks of digital interventions for individuals, healthcare providers and health systems. Specific examples highlighted in this section include genomics and molecular surveillance; big data and algorithms; and artificial intelligence and machine learning.

#### 4.1 Genomics and molecular surveillance

Genomics is the study of genes and their interrelations to identify their combined influence on human development.<sup>127</sup> Genome-editing technologies that can recognize specific DNA sequences hold much promise for curing HIV through the ability to systematically search the human genome (i.e. all the genetic information in a person) for common genetic variants that influence the human response to HIV acquisition. Identification of these variants can inform targets for intervention, whether through a preventative vaccine or antiretroviral treatment.<sup>128</sup> Benefits of these technologies include specificity to individuals, ease of use, and ability to be custom-designed for treating individuals.

Molecular surveillance is the aggregate use of an individual's HIV treatment resistance data to identify and respond to HIV transmission clusters, or a group of persons with diagnosed HIV infection who have genetically similar HIV strains.<sup>129</sup> Clusters are difficult to identify with epidemiological methods – molecular data are needed to identify areas of higher transmission. The aim of molecular surveillance is to track trends in HIV epidemiology by identifying social networks at high risk of HIV transmission in order to better target preventative interventions. This manner of tracking HIV cases and trends is controversial among communities of people living with HIV and other civil society groups, with particular concern over the use of phylogenetics and criminalization of HIV non-disclosure, exposure and transmission.<sup>130</sup>

#### 4.2 Big data and algorithms

'Big data' refers to the collection of a significantly large amount of data, often growing in three dimensions – volume, velocity and variety – that cannot be handled by traditional methods or data processing software packages.<sup>131</sup> Digital technologies collect and process massive amounts of data, potentially from various sources (e.g. government administrative data, social media, Internet searches) as well as metadata (e.g. data that describes other data). A related but distinct concept connected to big data is algorithms, which are a set of programmed rules or processes applied to analyse data for a specific purpose or output.<sup>132</sup>

Scientists posit that big data and algorithms have significant utility for addressing HIV among key populations due to the increased availability of an unprecedented amount of data including from individuals' mobile technologies.<sup>133</sup> There are numerous applications of big data and algorithms for HIV-related programmes. Examples include systems integration of different sectors to track HIV in the mining industry<sup>134</sup> and using web search engine data to predict new HIV cases.<sup>135</sup> Benefits of using big data and algorithms include: increased capacity to collect vital information to inform programme development to improve health outcomes, and promotion of cross-sectoral data sharing to increase provider coordination and collaboration.

#### 4.3 Artificial intelligence and machine learning

Artificial intelligence (AI) is "the development of computer systems to perform tasks that usually require human intelligence, such as visual perception, speech recognition, and decision-making".<sup>136</sup> AI, which also encompasses the subfields of machine learning, natural

language processing and robotics, has countless applications to public health sciences and the delivery of HIV-related programmes. For example, researchers have developed a machine learning model to identify patients at risk of dropping out in order to improve retention in HIV treatment and care.<sup>137</sup> This field also includes conversational AI, which can increase accessibility of services to people with lower literacy and physical disabilities. Benefits of AI use include: improved quality of care by supporting providers to more accurately diagnose patients and choose corresponding treatment plans, and enhanced ability to slow the spread of disease through modelling and predictive epidemiological efforts.<sup>138</sup> AI application provides the opportunity to significantly improve the efficiency of healthcare delivery and quality of patient care.

### Using artificial intelligence to provide health information to deaf and hearing-impaired persons

UNDP, Egypt's Ministry of Communication and Information Technology and Avaya developed an automated testing service which uses accessible chatbots and artificial intelligence technology in sign language to enable access to information for hearing impaired. The chatbot asks users several questions using sign language to determine whether they are experiencing COVID-19 symptoms and refers them to the responsible government agency to appropriate care.

Source: Adapted from UNDP Egypt brief: *Artificial intelligence is leaving no one behind: Accessible chatbot for deaf and hearing-impaired persons* (2 June 2020). Available from [www.eg.undp.org/content/egypt/en/home/stories/2020/artificial-intelligence-is-leaving-no-one-behind--accessible-cha.html](http://www.eg.undp.org/content/egypt/en/home/stories/2020/artificial-intelligence-is-leaving-no-one-behind--accessible-cha.html)

## 5 Digital health technologies to advance drug research and development

Technological applications in drug research and development are wide-ranging and include AI and machine learning, among other digital approaches. Benefits of digital technology-enabled drug product research and development include greater efficiency in screening drug candidates among existing drugs, and using machine learning approaches for the identification of prognostic biomarkers to determine the likelihood of disease occurrence for an individual.<sup>139</sup> AI and machine learning can also be used to rapidly analyse digital pathology data in clinical trials. Drug research and development also draws on genomic sequencing and developing nanotechnology for enhanced treatment.<sup>140</sup>

## 6 Use of digital technologies during the COVID-19 pandemic

The COVID-19 pandemic accelerated the use of digital health technologies. Since conventional public health methods are slow and subject to human error, many countries are turning to them to support their COVID-19 responses. Basic eHealth approaches, including online COVID-19 data dashboards and mobile phone apps for contact tracing and case management, have complemented new digital technologies such as infrared thermal screening cameras and wearables (e.g. smartwatches) that monitor temperature, pulse and sleep pattern data to screen for the disease.<sup>141</sup>

### Georgia's e-Learning Platform to enhance infection prevention and control

In the wake of the first wave of COVID-19, UNDP with the support of Sweden worked with the National Center for Disease Control (NCDC) in Georgia to build an e-learning platform that provides medical professionals and administrative staff with opportunities to receive training, communicate, exchange experiences, and receive practical advice from NCDC experts. The platform is available to 37 medical institutions and the NCDC's 60 regional centres across the country. 3,000 medical workers from the clinics designated for COVID-19 treatment and 1,000 medical staff from regular health-care institutions have been trained in health emergency response. Also, this training was also provided to operators of a specialized hotline for medical professionals who will be trained in infection prevention and control. The e-learning platform operates through desktop and mobile applications, with a built-in chatbot and search engine, allowing for real-time consultations and exchange.

Source: Adapted from UNDP (2020) "Boosting Georgia's public health care with digital solutions". New York. Available from [www.ge.undp.org/content/georgia/en/home/press-center/pressreleases/2020/covid-health-care-elearning.html](http://www.ge.undp.org/content/georgia/en/home/press-center/pressreleases/2020/covid-health-care-elearning.html).

New algorithms and AI, which includes analyses of big data collected in relation to COVID-19, have made it possible to develop digital health interventions for COVID-19. Digital technologies are playing an important part in vaccine rollouts, and harnessing the power of AI and data analytics will be crucial for increasing equitable access to COVID-19 vaccines.

### Indonesia's innovative technology supporting COVID-19 vaccination rollout

UNDP's Sistem Monitoring Imunisasi Logistik Secara Elektronik (SMILE), an innovative technological solution that aims to strengthen the immunization supply chain system in Indonesia, will be engaged to ensure the delivery of vaccines across the archipelago. Developed in 2018, SMILE aims to strengthen the health supply chain for Indonesia's immunization programme by managing vaccine stocks and quality. This has helped improve efficiency, especially in terms of reporting and monitoring real-time data of vaccine stocks. The SMILE app will be used to track delivery to COVID-19 health facilities.

Source: Adapted from UNDP (2020) "COVID-19 Immunization Drive provides opportunity for Indonesia to adopt UNDP's Digital Tracking System. New York. Available from [www.id.undp.org/content/indonesia/en/home/presscenter/articles/2020/Smile-Vaccine.html](http://www.id.undp.org/content/indonesia/en/home/presscenter/articles/2020/Smile-Vaccine.html).

While digital technologies may hold promise to support more effective public health responses, it is imperative to flag that such interventions may also be prone to error, perpetuate entrenched biases as well as present privacy and confidentiality risks, particularly where mass surveillance is involved. Thus, ensuring safeguards to protect individual rights, including through regulatory frameworks, is paramount when considering the adoption of digital health technologies.

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