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

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Acknowledgments

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Introduction

section 1

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.¹ 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".² 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 (SGD) targets, and for building more resilient systems for health.³

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.⁴ 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.⁵ Digital technologies facilitated pandemic strategies and responses in ways that would have been difficult to achieve manually.⁶ Digital health technologies (i.e. 'digital health')⁷ 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.⁸ 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."⁹ As countries work towards achieving the SDG 3 – *Ensure healthy lives and promote wellbeing 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.¹⁰ 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.¹¹ 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.¹² 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*,¹³ 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.

section 2

2.1

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.

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

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