Paying the Costs of Connection

WARWICK
THE UNIVERSITY OF WARWICK
CENTRE FOR INTERDISCIPLINARY METHODOLOGIES (CIM)

DHRP
Digital Health & Rights Project

Human rights of young adults in the digital age in Colombia, Ghana, Kenya and Vietnam.

Executive Summary

The digital transformation is revolutionising health systems and access to health information. While these advances have improved healthcare access in low- and middle-income countries (LMIC), deep inequalities have created "digital divides" that leave many without access to essential information and services. Efforts to regulate digital platforms have struggled to keep up with the pace of innovation. This is a particular concern for growing youth populations, many of whom are frequently online and whose voices are rarely heard in digital health governance.

This study–the largest of its kind–focused on Colombia, Ghana, Kenya and Vietnam. We interviewed 301 young adults ages 18-30 who were either living with HIV, sex workers, gay men and other men who have sex with men, transgender or gender diverse, or cisgender women. We also interviewed 40 experts from UN agencies, government and civil society.

Findings include:

- Many participants described struggling to get online, due to cost of smartphones and data bundles, lack of Wi-Fi, lack of digital skills, or lack of ability to assess reliable health information.
- Young women talked more about these issues than young men and described financial dependence on partners or supervision by family members as challenges.
- For people living with HIV and members of stigmatised groups, fears of poor data protection or of being outed to the community made them reluctant to seek health information online.
- Three-quarters of young adults described technology-facilitated abuse, including verbal abuse, doxxing, stalking, blackmail, and extortion, against themselves or peers. Abuse included severe physical violence. Abuse appeared increasingly normalised among young adults.
- HIV activists and peer outreach workers said their outspoken advocacy for health rights exposed them to virulent verbal abuse and threats.
- Few of the young adults we spoke to had been successful when reporting abuse to online platforms, or in getting access to redress.
- Some were reluctant to report abuse to the police, either because they were not sure whether the abuse was legal; or because of laws criminalizing sex work and same-sex sexual relations in their countries; or due to past experiences of police abuse.
- Community-led groups were a key source of support. In one case, Vietnamese HIV activists in the study's project advisory committee used that committee as a platform to mobilize and respond to viral online abuse. This showed that, in their view, community-led HIV advocacy networks could be an effective model for addressing technology-facilitated abuse.
- Study participants expressed resilience, determination and a strong interest in getting training in-person and online about their rights, artificial intelligence (AI), we call this "digital empowerment".
- Many had optimistic visions of the future and called for greater accountability and transparency online, to ensure this future is realised.

STOP AIDS.
VNP+ VIETNAM NATIONAL NETWORK OF PEOPLE LIVING WITH HIV
Universidad de los Andes Colombia
fondation BOTNAR
GNP+ GLOBAL NETWORK OF PEOPLE LIVING WITH HIV
KELIN Reclaiming Rights, Rebuilding Lives
RESTLESS DEVELOPMENT
NETWORK OF PERSONS LIVING WITH HIV/AIDS GHANA

Since 2019, the Digital Health and Rights Project (DHRP) consortium has brought together social scientists, global and national networks of people living with HIV, and civil society leaders, collaborating to conduct community-engaged research and use findings to inform global health governance. The study is one of the largest international studies of digital human rights in health to date, and one of the few using a transnational participatory action research approach. It is built on previous smaller studies led by DHRP that used participatory and community-engaged approaches to study the digital transformation of health and human rights; as well as on DHRP's support to the mandate of the UN Special Rapporteur on the Right to Health for her 2023 report on digital innovation, technology and the right to health to the UN Human Rights Council. Since 2021, DHRP has now cumulatively engaged over 600 young adults in qualitative research into human rights and digital health.

In our transnational participatory action research approach, study participants engaged in every step of the process. The transnational research team was led in each country by national institutions, with national principal investigators at Universidad de los Andes (Colombia), Kenya Legal & Ethical Issues Network on HIV and AIDS (KELIN Kenya), the Ghana Network of Persons living with HIV (NAP+ Ghana), and the Vietnam Network of People Living with HIV (VNP+). They established national Community Advisory Teams made up of young adults from the study populations, as well as health advocacy groups and human rights groups, who advised the research project at national levels through advisory committees, participated as researchers, validated the findings, led national advocacy plans based on the research findings, and elected representatives to the project's governance board. They were trained in youth leadership, advocacy, digital governance, and media outreach, and helped to draft the recommendations.

The study was supported by a principal investigator and research team at University of Warwick. Global advocacy is led by STOPAIDS and Privacy International (UK), with youth leadership supported by Restless Development and guidance by the Global Network of People Living with HIV (GNP+).

> "Digital inclusion has become fundamental to the right to health."

Recommendations

For governments, technology companies, funding agencies and UN technical agencies.

1. **Digital inclusion is fundamental to the enjoyment of human rights.**
   To tackle exclusion, we must identify the many intersecting challenges that individuals face in securing digital access, and develop supportive interventions to address them: Progressively improving quality network coverage, including in rural areas; offering access to smartphones and free or low-cost data, and structural changes. Health services must not exclusively rely on digital access.

2. **Technology-Facilitated Abuse (TFA) requires urgent action.**
   TFA affects women, and also men, transgender people, people living with HIV, sex workers, and HIV activists/peer outreach workers who share health information online. Abuses may move between online and offline. We call for a survivor-centred approach that upholds confidentiality and autonomy of survivors. Governments must strengthen regulation of the private sector, train lawmakers and law enforcement, and raise public awareness to ensure access to redress for survivors. Technology companies must have complaints procedures in place, in line with human rights standards. Funders should invest in research to deepen understanding of the root causes and drivers of TFA and document cases.

3. **We call for robust action by governments to protect the right to privacy in the digital age,** particularly for young adults who are living with and affected by HIV, by strengthening data protection laws and ensuring their proper enforcement. This also requires informing the public about their rights to data protection, and options for remedy if rights are infringed. Technology companies should conduct human rights due diligence, mitigate possible harms, and ensure access to redress.

4. **Given current cuts to aid, we call for continued investment in the resilience and leadership of young adults;** including investments in digital literacy and Know Your Rights training, and in civil society leadership to train, reach and engage historically marginalised populations. Young adults, women, people living with and affected by HIV, and civil society groups from LMIC must have a seat at the table to participate meaningfully in the decisions that affect their lives, including digital governance.

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