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DIGITAL HEALTH AND HUMAN RIGHTS OF YOUNG ADULTS IN GHANA, KENYA, AND VIETNAM

FINAL PROJECT REPORT

DIGITAL HEALTH AND RIGHTS PROJECT

GENEVA
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Contact

For further information, please contact Principal Investigator, Sara L.M. Davis, via email: sara.davis@graduateinstitute.ch

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Global Health Centre

Graduate Institute of International and Development Studies
Chemin Eugène-Rigot 2 | Case Postale 1672
1211 Geneva 21 | Switzerland

Tel: +41 22 908 4558

Fax: +41 22 908 4594

Email: globalhealth@graduateinstitute.ch

> graduateinstitute.ch/globalhealth

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DIGITAL HEALTH AND RIGHTS PROJECT ADVISORY COMMITTEE

Kenechukwu Esom, UNDP* – *Committee Chair*
Rasha Abdul-Rahim, Amnesty Tech
Wisdom Atiwoto, Ghana Ministry of Health
Mushtaque Chowdhury, Bangladesh Health Watch
Robert Cryer, The Global Fund
Tim Dagori, iHub
Amy Dao, California State Polytechnic University
Maarja-Liis Ferry, Students for Global Health
Yolokazi Mfuto, UNFPA Youth Panel
Tlaleng Mofokeng, UN Special Rapporteur on the Right to Physical and Mental Health
Cathy Mwangi, mHealth Kenya
Sandra Rotzinger, GIZ
Keith Sabin, UNAIDS
Tigest Tamrat, World Health Organization
Christiaan Van Veen, NYU Digital Welfare State and Human Rights Project
Sara (Meg) Davis, *ex officio*

*Affiliations provided for identification purposes only

ABBREVIATIONS

AI	Artificial intelligence
GHS	Ghana Health Service
GNP+	Global Network of People Living with HIV
HIC	High-income countries
LGBTQ+	Lesbian, gay, bisexual, transgender, queer
LMIC	Low- and middle-income countries
NAP+ Ghana	National Association of People Living with HIV in Ghana
PLHIV	People living with HIV
SGBV	Sexual and gender-based violence
SRH	Sexual and reproductive health
UNAIDS	Joint United Nations Programme on HIV and AIDS
UNDP	United Nations Development Programme
VNP+	Vietnamese Network of People Living with HIV (VNP+).
WHO	World Health Organization

EXECUTIVE SUMMARY

Background

“Digital health” is defined by the World Health Organization (WHO) as describing digital technologies used for health promotion, health service delivery, supply chain management, health financing, human resource management and data services. The digital health sector is growing rapidly, with new pilots and initiatives attracting significant investment from the public and private sectors. International agencies actively promote the digital transformation for development; in 2020, the World Health Assembly approved a *Global Strategy on Digital Health 2020-2025*, which committed member states to develop and implement national digital health strategies. However, UN human rights experts have also raised concerns about related threats to human rights and have called for more robust and rights-based digital governance.

Objectives and methods

This report investigates how young adults in Ghana, Kenya and Vietnam experience the digital transformation in health, and what they see as the effect on their human rights. In particular, the study explores the tensions between the benefits and risks to young peoples’ right to health and other human rights, and identifies areas for policy action.

The study utilised qualitative methods and a transnational participatory action research (PAR) approach, in which the communities being studied participated in the design, implementation and analysis of the study. The research team included academic social scientists working in collaboration with staff of national community-led networks, human rights groups, and civil society organisations. The researchers drew on law and policy analysis; digital ethnography; focus group discussions with 174 young adults in seven cities across all three countries; and 33 key informant interviews with UN officials, government officials, tech experts, and civil society leaders. Qualitative analysis was used to identify themes and patterns in the data. The findings and policy recommendations were discussed and validated with study participants. While the research drew on the infrastructure and experience of global and national networks of people living with HIV, the study looked broadly at HIV, SRH, Covid-19, and other related human rights concerns.

Findings

The study finds both significant empowerment potential and significant risks in the digital transformation of health. In particular, it shows that young people increasingly rely on their mobile phones to access health information and services through Google searches, social media networks (such as Facebook, Instagram, YouTube and TikTok), and social chat groups (such as WhatsApp). A smaller number of young adults described using dedicated mHealth apps.

Young people expressed enthusiasm for accessing health information through these channels, because they believed their anonymity was protected online, enabling them to avoid the stigma they had experienced in clinics. Young women said they actively seek health information for themselves, their peers and less digitally-literate older relatives.

The use of social media for health information offers both benefits and risks. On the positive side, the study documents the rise of innovative social media health champions who offer youth-friendly information and advice, who make an effort to ground their advice in medically sound sources, and who successfully create safe spaces online for discussion of sensitive topics with young people. Young people emphasised the importance of these “online families” and “safe spaces”, especially given mental health pressures during the Covid-19 pandemic. Some social chat groups provided essential access to medicines, financial aid and psychosocial support during Covid-19 isolation. In some cases, such groups also serve as the only available meeting space for criminalised and marginalised groups.

However, young people in all three countries also disclosed serious harms. These included misinformation; censorship of health information; anxiety about phone “addiction”; verbal abuse

and threats; public shaming; sexual harassment and stalking; extortion and blackmail; and physical violence. These harms were especially reported by young women, LGBTQ+ people, and sex workers. Some young people also expressed anxiety about risk of online surveillance, considering criminalization of abortion and same-sex sexual behavior. These harms lead some young people to limit their online participation, impacting their access to health information and services.

The study also finds profound inequalities in access. Structural factors shaping access included gender, economic resources, rural/urban disparities, educational level, disability, sexual orientation and gender identity, religious and cultural norms, and more. For some groups, such as sex workers, these inequalities are intersectional in nature, combining to create profound exclusion, greater risks, and less access to redress. As one young woman in Kenya put it, sexual harassment, threats and extortion “are just something you have to deal with as an individual.”

The researchers’ review of laws and policies in all three countries found that these issues were not addressed in national laws and policies. Given the central role of technology companies in high-income countries in providing and limiting access to health information, the study finds that “data colonialism”, or the extraction of young peoples’ health data for private benefit in HIC, may limit use of this data to strengthen LMIC health systems. Our review also found that the use of social media, social chat and web searches for health information and peer support is generally not addressed in global health strategies and policies.

While all three countries have data protection laws and policies, key informants in each country described implementation and enforcement as weak. Young people in the study generally had little knowledge of these laws or their rights. Many expressed enthusiasm, nonetheless, to learn more about digital technologies and governance, and to play an active role in the digital transformation. They called for more resources and training, and a voice in policy.

Policy recommendations

Key Actors	Recommendations
UN and other global health agencies	Commit to rolling out existing guidance on ethics, human rights and digital health at national levels, including training and technical support to country offices and member states
	Develop and promote new guidance outlining the norms, laws and policies that need to be in place for states to respect, protect and fulfil human rights with the use of data and technology in health. This should include the meaningful participation of civil society and communities in decision-making
	Develop a set of evidence-based interventions to address digital divides and digitally empower young people
	Recognise web searches and social media in the definition of digital health
Donors (including Global Fund, bilateral donors, private foundations)	Fund interventions that digitally empower communities, including: digital rights and literacy training for communities, government and healthcare providers’ community-led initiatives, including quality of life initiatives that address mental health and wellbeing (e.g. safe online spaces), free data, and infrastructure investment to expand equitable, online access to health services and information, and effective use of social media and collaboration with online health champions when developing new mHealth apps.

National governments	Ensure affected communities and civil societies meaningfully participate in decisions from start to end, including the design of digital technologies and in the governance and oversight of their use in health
	Raise awareness amongst citizens, and educate government officials and policymakers, on laws, regulation and governance related to human rights in the use of data and technology
	Collaborate with local social entrepreneurs and social media health champions to reach young people with health information and services
	Plan for and invest in the enforcement of existing data protection and digital rights policies and ensure redress for online harms.
	Work with other governments and UN bodies to promote stronger regulation and accountability for social media companies

The Digital Health and Rights Project consortium (originally, the “Digital Health and Rights Advisory Group”) includes anthropologists at Graduate Institute Geneva (Switzerland), Universidad de los Andes (Colombia), BRAC University (Bangladesh), and University of Oslo (Norway); human rights lawyers at KELIN (an NGO in Kenya); health advocates at STOPAIDS (a civil society network in the UK); and the Global Network of People Living with HIV (GNP+) who are working together in a transnational participatory action research approach that combines research, reflection, analysis and policy engagement. The consortium is hosted at the Graduate Institute Geneva.

The Project Advisory Committee includes the UN Special Rapporteur on the Right to Health, Dr. Tlaleng Mofokeng; representatives of the Joint UN Programme on HIV and AIDS (UNAIDS), the Global Fund, WHO, the UN Development Programme (UNDP), and the German development agency, GIZ; health and technology experts from Ghana, Kenya and Bangladesh; as well as anthropologists, civil society leaders, and two youth representatives.

INTRODUCTION

Background

“Digital health” is defined by the World Health Organization (WHO) as describing digital technologies used for health promotion, service delivery, supply chain management, financing, human resource management and data services.¹

Digital health has boomed in recent years, with over \$29 billion in new investment in the US alone in 2021, a major increase over the past.² The Covid-19 pandemic has accelerated this trend, with more people than ever before using digital platforms to check symptoms, search for answers to questions, and consult with health providers. Digital health platforms and tools offer the potential to broaden access to, and improve quality of, health services, in part by producing new data that can be used to better design and pinpoint services, and empowering people to have greater control of their health and well-being.

At the same time, the rapidly-growing digital transformation is rife with risks: political manipulation through social media, health misinformation and disinformation, data breaches and attacks on health clinics, cyberbullying and more. Technology companies now have the capacity to extract significant quantities of intimate information for private profit, with little restriction on its collection or use.

UN agencies have actively promoted the use of digital technologies and artificial intelligence (AI) in order to accelerate progress towards the Sustainable Development Goals (SDGs). In 2020, the World Health Assembly approved a *Global Strategy on Digital Health 2020-2025*, which committed member states to developing and implementing national digital health strategies.³

UN and development agencies have noted the challenges posed by gender inequalities. It is clear that fewer young women than men have access to the internet, and women are underrepresented in tech design and management. In Ghana, over 2.5 million fewer women are online than men.⁴

However, UN human rights experts have raised numerous other human rights concerns about the digital transformation, including threats to privacy, and the privatisation of welfare services, which have received less attention in the context of digital health.⁵ They have cautioned that algorithmic biases also amplify racial discrimination.⁶

The digital transformation also raises concerns in the context of geopolitical inequalities.

¹ World Health Organization (WHO) (2018). Classification of digital health interventions. WHO/RHR/18.06. <https://apps.who.int/iris/bitstream/handle/10665/260480/WHO-RHR-18.06-eng.pdf>

² Rock Health (2022). “2021 Year-end digital health funding: Seismic shifts beneath the surface.” Report, January 10. <https://rockhealth.com/insights/2021-year-end-digital-health-funding-seismic-shifts-beneath-the-surface/>.

³ WHO (2020). *Global strategy on digital health 2020-2025*. <https://www.who.int/docs/default-source/documents/gS4dhdaa2a9f352b0445bafbc79ca799dce4d.pdf>.

⁴ GSMA (2020). *Mobile Gender Gap Report 2020*. <https://www.gsma.com/mobilefordevelopment/wp-content/uploads/2020/05/GSMA-The-Mobile-Gender-Gap-Report-2020.pdf>

⁵ UN Human Rights Council (2019), *Report from the Working Group of experts on people of African descent* A/HRC/42/59; UN General Assembly (2021), *The Guiding Principles on Business and Human Rights: guidance on ensuring respect for human rights defenders* A/HRC/47/39/Add.2; UN General Assembly (2019), *Report of the Special Rapporteur in the field of cultural rights* A/74/255; UN General Assembly (2018), *Right to development* A/73/271; UN General Assembly (2021), *Disinformation and freedom of opinion and expression* A/HRC/47/25; UN General Assembly (2022) *Rights of persons with disabilities* A/HRC/49/52; UN General Assembly (2019), *Report of the Special Rapporteur on Extreme Poverty and Human Rights*, A/74/493 (2019); UN Human Rights Council (2016) *Promotion and Protection of Human Rights on the Internet*, A/HRC/32/L.20; UN High-Level Panel on Digital Cooperation (2019), *The Age of Digital Interdependence: Report of the UN Secretary-General’s High-Level Panel on Digital Cooperation*, <https://digitallibrary.un.org/record/3865925?ln=en>; UN High Commissioner for Human Rights (OHCHR) (2021), *The Right to Privacy in the Digital Age*, A/HRC/48/31; OHCHR (2018), *The Right to Privacy in the Digital Age* A/HRC/39/29.

⁶ OHCHR (2020). “Emerging digital technologies entrench racial inequality, UN expert warns.” Press release, July 15. <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=26101&LangID=E>

Mobile phone applications, including social media, are often intentionally designed to encourage high rates of user engagement.⁷ High rates of user engagement enable extraction of personal data for sale to third parties, or for development of new products.⁸ The European Union General Data Protection Regulation restricts the processing of personal data, but does not protect those outside the EU, so that technology companies whose access to data in the Global North may be restricted may seek it in the Global South. The extraction of data from the Global South for profit in the Global North has been called a form of “data colonialism”.⁹

In this context, young people in low- and middle-income countries (LMIC) may face special vulnerability. Young people are more populous in LMIC due to the demographic transition, and many young people are increasingly online. In 2020, 71% of young people (15-24 years of age) used the internet, compared to 57% of the world’s population on average. Even in the poorest countries, where internet use is much lower, young people are more likely to log on (in least developed countries, 34% of young people use the internet compared to the total population average of 22%).¹⁰ Young peoples’ data is especially valuable to the private sector, because of the insights they offer into future consumer trends; their data can also be used to tailor advertising and train algorithms.¹¹ High rates of user engagement promoted by mobile phone apps may cause harm to young adults: evidence is accumulating that problematic cell phone use, aka “phone addiction”, negatively impacts mental health.¹² Yet young people have little awareness of or input into the decisions that shape what kinds of data are gathered about them, by whom, and how that data is used or managed by others, in their own countries or beyond.

Given all these concerns, we identified a need for more empirical evidence of the positive and negative effects of the digital transformation on health-related human rights of young people in LMIC. The study aimed to investigate how young people use mobile phones for HIV, sexual and reproductive health (SRH), and Covid-19 information and services; and what young people identify as the benefits and risks to their human rights.

Our approach is grounded in human rights, as a significant body of research has established that laws and policies impact on health service access and uptake, work highlighted by the Global Commission on HIV and the Law, among others.¹³ In Nigeria, for example, the passage of the Same-Sex Marriage Prohibition Act had an immediate and measurably negative effect on health service access for men who have sex with men.¹⁴ Human rights standards have effectively been used by networks of people living with HIV for global mobilisation and high-level advocacy. In

⁷ Hartmans, A. (2018) “These are the sneaky ways apps like Facebook, Instagram, Tinder lure you in and get you ‘addicted’.” *Business Insider*, Feb 17. <https://www.businessinsider.com/how-app-developers-keep-us-addicted-to-our-smartphones-2018-1?r=US&IR=T>

⁸ Zuboff, S. (2019) *The age of surveillance capitalism: The fight for a human future at the new frontier of power*. London, UK: Profile Books.

⁹ Couldry, N. and Mejias U.A. (2019) “Data Colonialism: Rethinking Big Data’s Relation to the Contemporary Subject.” *Television and New Media* (20:4). DOI: <https://doi.org/10.1177/1527476418796632>.

¹⁰ International Telecommunications Union (ITU). (2021). *Measuring Digital Development: Facts and figures 2021*, p. 5. <https://www.itu.int/en/ITU-D/Statistics/Pages/facts/default.aspx>.

¹¹ UK Children’s Commissioner (2022). *Who knows what about me?* <https://www.childrenscommissioner.gov.uk/digital/who-knows-what-about-me/>

¹² Gutierrez J. D-S., de Fonseca F.R., and Rubio G. (2016). “Cell phone addiction : A review”. *Front. Psychiatry Sec. Addictive Disorders*, 24 Oct. DOI: <https://doi.org/10.3389/fpsy.2016.00175>

¹³ See, for example, evidence collated in two reports for the Global Commission on HIV and the Law (2012) *HIV and the Law: Risks, Rights and Health*, NY: UNDP and (2018) *HIV and the Law: Risks, Rights and Health – Supplement*. Both are available on <https://hivlawcommission.org>.

¹⁴ Schwartz, S. R., Nowak, R.G, Orazulike, I., et al. (2015). “The immediate effect of the Same-Sex Marriage Prohibition Act on stigma, discrimination, and engagement on HIV prevention and treatment services in men who have sex with men in Nigeria: Analysis of prospective data from the TRUST Cohort.” *The Lancet HIV* (2:7): e299-306. DOI: [https://doi.org/10.1016/S2352-3018\(15\)00078-8](https://doi.org/10.1016/S2352-3018(15)00078-8).

2021, the *Lancet/Financial Times Commission on Global Health Futures 2030* called for rights-based and inclusive governance of digital health, with young people at the centre.¹⁵

About the Digital Health and Rights Project

The Digital Health and Rights Project consortium (originally, the “Digital Health and Rights Advisory Group”) came together in 2019 to develop a shared research and policy agenda. The consortium includes anthropologists at the Graduate Institute Geneva (Switzerland), Universidad de los Andes (Colombia), BRAC University (Bangladesh), and University of Oslo (Norway); human rights lawyers at KELIN (an NGO in Kenya); HIV activists at STOPAIDS (a civil society network in the UK); and people living with HIV at the Global Network of People Living with HIV (GNP+). The consortium are working together in a participatory action research approach that combines ethnographic research, reflection, analysis and policy engagement to:

- Use ethnographic field research to develop case studies of mobile apps and social media used to address HIV, TB, Covid-19 and sexual and reproductive health in Kenya, Ghana, Vietnam, Bangladesh and Colombia.
- Assess what legal and policy frameworks are used to implement these tools, how they are governed, how human rights concerns are addressed, and how integrated youth and civil society are in decision-making for these tools;
- Develop a set of global health policy recommendations grounded in human rights principles and legal and ethnographic research, and in the lived experience of affected communities; and
- Empower transnational youth activist networks with the knowledge, networks and opportunities to raise the recommendations in health policy in national and global health governance.

The study’s Project Advisory Committee includes the UN Tech Envoy, Prof. Amandeep Gill; UN Special Rapporteur on the Right to Health, Dr. Tlaleng Mofokeng; representatives of the Joint UN Programme on HIV and AIDS (UNAIDS), the Global Fund, WHO, and the UN Development Programme (UNDP); health and technology experts from Ghana, Kenya and Bangladesh; a bilateral health agency, GIZ; as well as anthropologists, civil society leaders, and two youth representatives.

The first phase of the research (2020-22) focuses on Ghana, Kenya and Vietnam. A second phase (2021-23) will examine the same questions in Bangladesh and Colombia.

¹⁵ Kickbusch, I., Piselli, D., Agrawal, A., et. al. (2021). “The Lancet and Financial Times Commission on Governing Health Futures 2030: Growing up in a digital world.” *The Lancet* 398 (10312): 1727–76. [https://doi.org/10.1016/S0140-6736\(21\)01824-9](https://doi.org/10.1016/S0140-6736(21)01824-9).

RESEARCH DESIGN AND METHODS

Research questions

The study has investigated the following questions:

- how digital health technologies are being piloted and brought to scale to provide information and services related to HIV, SRHR, Covid-19,
- how young adults – especially those living with HIV, young women, young key populations (sex workers, people who use drugs, transgender people and men who have sex with men) -- experience and manage the effects of digital technologies on their personal equity, autonomy, privacy and equality,
- the risks of harm and the empowerment potential of digital health for young people,
- who shapes the agenda in digital health, and what voice young people and community groups have in these processes (if any), and
- overall, what discourses and tensions are emerging in the digital transformation in health.

In the context of human rights, we considered the following concerns:

- The right to non-discrimination, including based on gender, sexual orientation and other protected status
- The right to the highest attainable standard of physical and mental health
- The right to privacy
- The right to security of the person
- The right to redress
- The right to benefit from science
- The right to freedom of association and assembly
- The right to freedom of information
- The right to freedom of expression and opinion

These human rights are upheld in international human rights treaties ratified by most countries, including Ghana, Kenya and Vietnam.

Transnational Participatory Action Research (PAR) approach

Our study applied a transnational approach to participatory action research (PAR). PAR engages study subjects as partners in design, implementation and analysis of research, reflecting on the findings for policy action.¹⁶ Multicountry health studies have found that PAR increases applicability of findings and builds long-term ownership of interventions.¹⁷ The approach is consistent with a growing demand for citizen science in global health; and with UN member states' commitment to increasing community-engaged research in the 2021 *UN Political Declaration on HIV and AIDS*.¹⁸

This study is one of the first to apply PAR transnationally. The transnational PAR approach offers some unique features. We collaborated within and across national borders in design and implementation of research protocols, tools and in data analysis. We benefited from the

¹⁶ Baum, F., MacDougall, C., and Smith, D. (2006). Participatory action research. *Journal of epidemiology and community health*, (60:10), 854–857. <https://doi.org/10.1136/jech.2004.028662>

¹⁷ Ozano, K., Dean, L., Adekeye, O., et al. (2020) "Guiding principles for quality, ethical standards and ongoing learning in implementation research: multicountry learnings from participatory action research to strengthen health systems." *Health Policy and Planning* (35): ii137–49.

https://academic.oup.com/heapol/article/35/Supplement_2/ii137/5959260?login=true; Worthen, M., Veale, A., McKay, S., Wessells, M. (2019) "The transformative and emancipatory potential of participatory evaluation: Reflections from a participatory action research study with war-affected young mothers." *Oxford Development Studies* (47): 154–70.

<https://www.tandfonline.com/doi/citedby/10.1080/13600818.2019.1584282?scroll=top&needAccess=true>

¹⁸ Tan, Y.R., Agrawal A., Matsoso M.P., et. al. (2022). "A call for citizen science in pandemic preparedness and response: Beyond data collection". *BMJ Global Health* (7) e009389; UN General Assembly (2021). *Political declaration on HIV and AIDS: Ending inequalities and getting on track to end AIDS by 2030*. A/RES/75/284.

participation and support of the global network of people living with HIV, and national networks. We facilitated field research exchanges among researchers in different countries. Researchers co-authored comparative desk reviews, and met online weekly to compare learnings. Researchers with academic training shared technical knowledge, and those with community experience shared advice on how to work with marginalised young people respectfully. This transnational approach to PAR enabled us to enrich the research plans and analysis with diverse forms of knowledge.

We worked with global advocates to develop policy recommendations suitable for both national and global agencies, enabling us to disseminate research findings through established roles in national health coordination mechanisms, global health governance boards, and advisory boards.

The research was led by a principal investigator (PI) at the Graduate Institute in Geneva, in collaboration with co-PIs at the National Association of People Living with HIV in Ghana (NAP+ Ghana), KELIN in Kenya, and the Vietnamese Network of People Living with HIV (VNP+). Researchers at each national organisation participated in study design, ethics and methods training, interviews and focus group discussions, and data analysis. They co-authored working papers based on desk reviews, and participated in field research exchanges.

The PI provided ongoing support and coaching, with additional support from GNP+ South Africa office and University of Oslo. The full consortium approved the protocol, tools and analysis. A project advisory committee, including two young members, received regular briefings and provided guidance.

STOPAIDS led development and implementation of a consortium advocacy strategy, using the evidence to develop policy recommendations. Members of the consortium shared learnings from the study iteratively in webinars with youth and community networks; in academic conferences such as the American Anthropological Association, and civil society convenings such as RightsCon and the International AIDS Conference; as well as integrating study learnings in their ongoing roles in global health governance and advisory committees at UNAIDS, UNDP, and the Global Fund.

Methods

Our qualitative methods included comparative review of laws and policies, digital ethnography, focus group discussions, and key informant interviews.

The three countries – Ghana, Kenya and Vietnam – exemplify diverse stages of digital transformation in three geographic regions (West Africa, East Africa, and Southeast Asia respectively). All three countries have young populations who experienced rapid increase in mobile phone use during the Covid-19 pandemic: in Kenya, mobile phone subscriptions increased to 61.4 million in December 2020, more than the national population (some individuals may register more than one phone); while in Vietnam, over 80% of the population over 15 years of age now owns a smartphone.¹⁹ Each country also has different HIV epidemics: Kenya has the highest HIV prevalence of the three countries, while Vietnam's epidemic is concentrated among young key populations. In Ghana and Vietnam, the national networks of people living with HIV were conducting PLHIV Stigma Index studies at the time of our study, and were keen to conduct further research.²⁰

¹⁹ MMA and Google (2020). *The state of mobile in rural Vietnam report 2018/2019*.

<https://www.mmaglobal.com/documents/state-mobile-rural-vietnam>

²⁰ Ayeh and Kpodo (2020). "Come together: Lessons learned from the engagement of key populations living with HIV in the People Living with HIV Stigma Index 2.0 implementation in Ghana". Community story. "The People Living with HIV Stigma Index" web page. <https://www.stigmaindex.org/community-stories/come-together-lessons-learned-from-the-engagement-of-key-populations-living-with-hiv-in-the-people-living-with-hiv-stigma-index-2-0-implementation-in-ghana/>.

Law and policy review: We reviewed laws, policies and strategies on digital governance and health in Ghana, Kenya and Vietnam; as well as international human rights standards and relevant court judgements. We published our analyses in two comparative working papers, one on international human rights norms, and one on national laws and policies.²¹

Digital ethnography: Researchers identified web sites, social media accounts and social chat groups in each country where young people seek and exchange health information, focusing on sites with higher rates of engagement. We used participant observation to identify trends, tensions and key actors.

Focus group discussions: We organised 24 focus group discussions with young adults ages 18-30: eight focus groups in Ghana (four in Accra, two in Kumasi and two in Tamale), eight in Kenya (four in Nairobi, four in Kisumu), and six in Vietnam (one in Ho Chi Minh City and five in Hanoi) between October 2021 and January 2022. In Vietnam, due to Covid-19 restrictions, focus group discussions were conducted via video conference.

Each focus group had six to eight participants. An interviewer aimed to elicit participants' experiences of using mobile phones to access health information and services, barriers to access, views of data governance, perceptions of benefits and risks, and recommendations. Focus group discussions lasted 90-120 minutes. Participants received travel subsidies and snacks.

Key informant interviews – The research team conducted semi-structured interviews with country directors and technical officers from UNAIDS, UNDP, WHO, PEPFAR and UNFPA; national and regional health officials; managers and technical staff of NGOs and private sector companies; doctors; social media account administrators; and leaders of networks of people living with HIV and key populations. Questions focused on trends in digital health governance, benefits and risks of digitization, barriers to access, and policy recommendations.

Recruitment - Researchers utilised purposive snowball sampling to recruit focus group participants, leveraging their institutional networks and reaching out to other civil society groups. Each participant selected a pseudonym and provided age, gender identity and occupation after providing informed consent.

Analysis - National organisations transcribed transcripts, and translated them into English where necessary. Two researchers reviewed each transcript. Four researchers conducted thematic analysis using Dedoose, and coded ten sample transcripts inductively. The codebook was refined using concepts identified in the desk review. The full consortium discussed and approved the codebook. Each transcript was coded by one coder; a selection was reviewed by a second coder.

Validation - In each country, national researchers discussed the draft findings and recommendations with study participants.

Ethics and security – Ethical risks in this study related to the participation of young adults whose identities are stigmatized or marginalized in the countries under study, including HIV status, sexual orientation and gender identity, or engagement in criminalized behaviors (such as same-sex sexual behavior, sex work or drug use). Those who volunteered such information in the course of the research project were reassured that what they said would be anonymized, and that data would be stored in a safe and secure manner. Informed consent procedures used clear

²¹ Mjwana, N., Imalingat, T., Kpodo, I., Pham, T. (2021) *Digital health and rights: Context in three countries – Ghana, Vietnam, Kenya*. Graduate Institute inception paper. https://repository.graduateinstitute.ch/record/299380?_ga=2.262551500.1356404449.1667151753-1295181159.1663151701; Davis, S., Were, N., Imalingat, T. (2021). *Digital health rights: Initial analysis*. Graduate Institute Global Health Centre working paper 27. https://repository.graduateinstitute.ch/record/299381?_ga=2.57643242.1356404449.1667151753-1295181159.1663151701.

and concise language developed and reviewed by community leaders in each country. All data was anonymized using codes, and identifiers were stored separately from field records in a secure and protected place. Protective measures were taken with regard to the transfer of data and sharing of data among partners. Participants were advised they could withdraw from the project at any time.

In each country, researchers followed the Covid-19 restrictions and regulations in place, including mask-wearing, provision of hand sanitizers, ensuring interviews took place in well-ventilated areas, and in some cases, moving the research online.

In consultation with each national organisation, all efforts were made to make participation feasible, diverse and inclusive, and to minimise the time commitment required.

Reflexivity - The study was conceived jointly among the principal investigator at the Graduate Institute and the executive directors of GNP+, STOPAIDS, and KELIN. Funding was based on a joint budget administered by the Graduate Institute. The consortium approved a shared data management and publications policy which affirms that the data is property of the national organisation.

The consortium does not claim to speak for young people. Rather, we utilised close listening strategies and drew on diverse expertise to develop a shared analysis.

RESULTS

Sample

A total of 181 young people participated in focus group discussion. After excluding those non-eligible due to age, participants included 174 young people, ages 18-30: 56 in Ghana, 71 in Kenya and 47 in Vietnam (*Table 1: Distribution of FGD participants*).

Table 1: Distribution of FGD participants

Ghana	56
Accra	27
Kumasi	20
Tamale	9
Kenya	71
Nairobi	34
Kisumu	37
Vietnam	47
Hanoi	39
Ho Chi Minh City	8
Total eligible participants	174

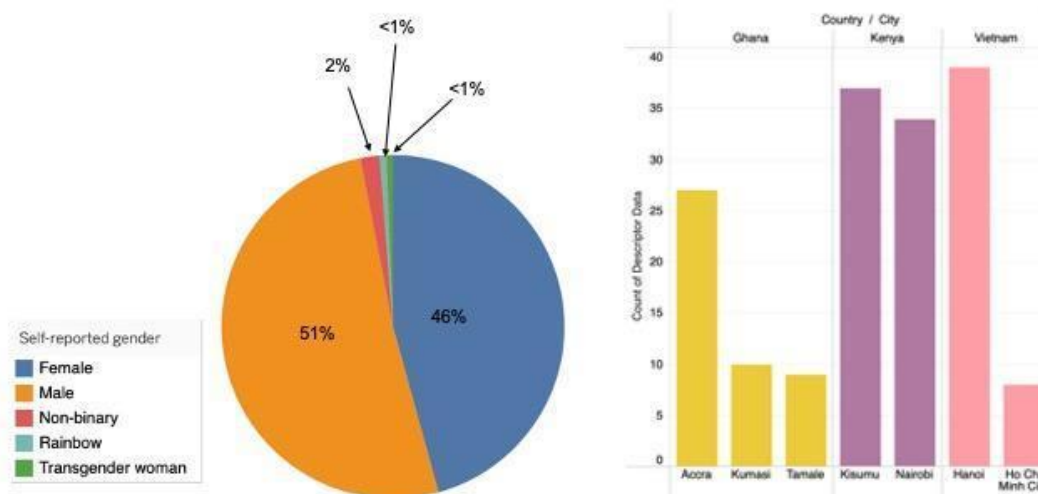
Chart 1 shows gender identities provided by participants, including women, men, transgender women, non-binary, queer, and rainbow. In Kenya, more women participated in the study, while more men participated in Ghana. In Vietnam, participants were recruited from national young key populations networks; gender identities were provided by community leaders, who reported only binary genders. However, transgender and non-binary people were likely in the sample.

Chart 1: Focus Group Discussion participants by gender identity and location²²

²² For the purpose of this report, we have used "queer male", "rainbow", "transgender" and other identifications as they were shared with us by study participants. Our consortium acknowledges that nuances of language are important, that we are applying an intersectional analysis and an anti-oppressive approach to our research, and that moving away from being heteronormative in our language while also being precise is an ongoing learning process for us.

Kenya, Vietnam, Ghana

Focus Group Discussion Participants by gender identity and location



The participants included university students, staff and peer outreach workers at health NGOs, journalists, teachers, restaurant service workers, individuals working in fashion or film, traders, construction workers, sex workers, and unemployed people.

Themes

Findings using all the methodologies are combined for the sake of concision.

Preference for web searches and social media

Most participants had little access to desktop or laptop computers, and described mobile phones as their main portal to health information. Most said they relied on web searches (Google), social media (Facebook, Twitter, YouTube, TikTok, Instagram), and social chat apps (WhatsApp in Ghana and Kenya, Zalo in Vietnam) for health information and advice. A smaller number said they used mHealth apps, such as menstrual tracking apps, pregnancy apps, and apps for mental health. In particular, in Kenya a number of participants said they consulted Aunty Jane, and in Ghana, many described using You Must Know. We found Flo, a British app for period cycle tracking, in use widely, even in remote regions in northern Ghana. However, most participants said web searches, social media and social chat were preferred.

In Nairobi, NBO-FGD1-N31 said,

Mostly [mHealth] apps are not used in the local community, maybe because they do not have smartphones, or just because of ignorance. Mostly people use Facebook.

A young HIV peer outreach worker in Accra (ACC-KII-C&D) said,

My clients who are comfortable with me prefer WhatsApp. But for those who want to stay anonymous, we use various apps: Twitter, Jodel, Grinder, Tinder. People who use such apps don't put their identity there.

Social media appeared to be preferred especially for younger people and those with less education.

In all three countries, participants said one key reason they preferred to seek information online was their experiences of stigma when seeking advice at clinics. For example, in Tamale, TML-

FGD1-C described leaving a hospital without completing her HIV test after meeting a judgemental healthcare worker. In Tamale, TML-FGD2-B said that he preferred to ask online for information about STIs and HIV, because he felt nurses would judge him as “an irresponsible and immoral young person.” In Accra, ACC-FGD1-E explained,

Yes, so, you can go, walk into the hospital and tell a service provider...I’m this and that, and I had sex, and I’m feeling this kind of way. And then she’s going to ask you, where, what kind of sex, and all that, you get me?

In Nairobi, NBO-FGD3-N18 said, “I think I can use my phone without being judged, like I can access some information without worrying someone is noticing.”

In some cases, more serious harm had occurred. In Kisumu, KSM-FGD4-K70 described sexual harassment by her doctor as one reason for her preference for online information. In Accra, two young men who identified as queer described “double discrimination” in clinics as men who have sex with men who are also living with HIV. One worried that Ghana’s proposed anti-homosexuality bill would require the Ghana Health Service (GHS) to start utilizing coercive conversion therapy, and said that due to the lack of any public statement to the contrary by GHS, “I would rather go online before telling anyone” of his health needs.

By contrast, young people with smartphones – young women in particular -- described themselves as being empowered by their access to online health information, which gave them authority and respect in their communities. For example, in Kisumu, a young woman (KSM-FGD3-K55) said,

I think I could have become a doctor during this Covid period... [because] most parents feared taking their kids to the hospitals. So, they just take my phone and Google the symptoms, and say, “This can be malaria”, and they take drugs.

While women across all three countries described themselves as seeking health information online frequently, men said they were more likely to reach out privately via WhatsApp to seek advice for mental health care. Several men described reluctance to seek health care, such as KSM-FGD3-K60 in Kisumu, who joked, “I think we men tend to keep illness or diseases private to ourselves, until we are at the verge of death -- and then we decide to go for help.”

Of course, while self-diagnosis online could lead to positive experiences of helping others, it also created risks of misdiagnosis, discussed further in the section on harms below.

In sum, while the study began initially with a focus on dedicated mHealth apps, once it became evident that these are less favoured by many young people than are Google and social media, the focus of our study shifted. We began to also consider how young people use their phones to search web engines and social media platforms for health information and advice, and to explore the tensions this creates between empowerment and vulnerability, safety and risk.

Social media health champions and “online family”

The low-cost barrier to accessing social media has created fertile ground for innovation. We found numerous grassroots initiatives that appeared to be meeting the demand from young people for safe access to health information, especially during Covid-19 restrictions. These initiatives ranged from large-scale social media accounts with tens or hundreds of thousands of young followers, to smaller-scale community-led chat groups for marginalised communities.

One such larger account is Love Matters Kenya, a Facebook group with over 1.8 million members which we found in the course of conducting digital ethnography. The site shares information on sexual and reproductive health, and fosters debate among thousands of followers about related sensitive topics, such as gender identity, sexual performance, abortion, and more. We also interviewed Karen “Kaz” Lucas, an Instagram influencer with over 30,000 followers in

Kenya, who told us she consults researchers and health experts in order to accurately answer SRHR questions she receives from her YouTube and Instagram followers.

In Vietnam, we interviewed the HIV activist behind *Phong's Story*, a YouTube account that shares HIV information with over 20,000 followers. In Ghana, young people told us they consult SHE+, an SRH hotline offered by NGO Savana Signatures in eight or nine Ghanaian languages, which reaches young people across the country who lack smartphones.

In each country, these social media health champions emphasised the importance of empathy, youth-friendly images and messages, and careful moderation of comments to create “safe spaces” that attract young people.

We also documented numerous grassroots initiatives led by civil society groups and volunteers. For example, in Nairobi, a sex worker (NBO-FGD1-N9) described how her community had established an online tool for documenting increased sexual and gender-based violence that occurred during the Covid-19 pandemic.

Individuals described how they had created their own accounts to share health information with peers. In Nairobi, NBO-FGD1-N20 described losing his cousin to suicide, and seeing another friend struggle with teen pregnancy. As a result, he said, he felt obliged to share what he could learn with others:

I feel there are other people in the community who are suffering from things. I took myself, like, let me be a vessel so as to address and to air their views.

He began regularly monitoring government health websites in order to explain what he found to social media followers.

In all three countries, we documented social chat groups where young people exchange health information on topics that ranged from diabetes, to nutrition, and pregnancy. One young woman who survived an ectopic pregnancy described starting a WhatsApp group to share information with her peers.

HIV peer outreach workers described using Facebook and WhatsApp groups to provide psychosocial support, treatment adherence advice, and coordinate medical and financial aid during Covid-19 restrictions. The chat group leaders said they discussed such topics as digital security, gender equality, gender identity, medications, Covid-19 vaccines, violence prevention, and coordination of emergency medical and financial assistance, among other topics. A Ho Chi Minh City-based civil society activist, HCM-KII-L, also described holding online sessions to answer questions about cybersex, to support young people to connect intimately and safely during Covid-19 restrictions.

In Vietnam, a member of the research team conducted ongoing digital ethnography in a Zalo (an app similar to WhatsApp) chat group for young people living with HIV. She documented how group members helped peers with hepatitis B or C to get early access to the Covid-19 vaccine; delivered food to those at need; and pooled funds to help a peer who had returned home in the last stages of AIDS. During strict Covid-19 travel restrictions, one member of the group reported that she had run out of antiretroviral medications and was afraid to request permission to travel to the clinic, as this would require disclosing her HIV status to local officials. Peers in the group privately delivered the refills to her, protecting her identity.

Some chat group leaders described a formal structure and agenda for their groups. In Nairobi, NBO-FGD3-N25 said that a young moderator leads her WhatsApp group, and invites experts for scheduled sessions:

Say today we're talking about HIV: We bring in a clinician. Today we're talking about TB, we bring in a TB clinician. So, there you get to access the correct information as well as referrals.

In Ghana, young gay men and other men who have sex with men said that given widespread homophobic violence and recent police raids, online chat groups had become the only safe means for their community to assemble. They described a standing agenda which included briefings on health and security, monitoring community members' treatment adherence, mapping high-risk areas of the city, and arranging home healthcare visits. In Kumasi, KSI-KII-ABC, a medical student, said:

I think it has created a bond between the community. It's more or less like a family, because at least we can help someone, if that person is in need. If that person is maybe sick and needs some small help, maybe that person is in an abused case, we just come in. We help ourselves a lot too, with some funerals, some parties. But the great benefit that we are getting out of it is the education that we are giving out, and the services that they are also receiving.

Many young people said that the links they have created to "online family" have created a deep sense of connection. In Kumasi, KSI-FGD1-H said,

My phone is *me*, because I have everything on my phone. If I'm a lesbian, I chat with my lesbian partners. If I am HIV-positive, I talk about it with my community people. My phone is me.

Intersectionality and the digital divide

As noted above, the digital gender divide has been widely documented. In addition to gender inequality, participants raised concerns about other structural factors shaping their access and confidence to the digital world. These included socio-economic class, language, disability, and rural/urban divides: 44% of Kenya's urban population has access to the internet, compared to 17% in rural areas.²³

Many participants raised the high cost of smartphones and airtime as concerns; in particular, women, transgender participants, and participants of all genders in Ghana. Several participants recalled wanting to search for health information online when they could not, because they lacked the funds to pay for airtime, and called for health information to be made available offline or free of charge. Others described having to share mobile phones with family members.

Several participants called on the government to provide free or low-cost airtime to enable their access to health information, noting that access to information is a basic right. Others highlighted the importance of toll-free hotlines and USSD text message services, such as SHE+ in Ghana and Aunty Jane in Kenya.

Language was frequently cited as a barrier to access: All three countries are linguistically diverse, but online information is frequently only provided in English or an official national language.

All these factors intersect with gender to shape power and vulnerability online.²⁴ The intersectional nature of the digital divide was highlighted during two focus group discussions in Accra held in parallel: one group with three female sex workers, and a second group of men who have sex with men (in fact, one person who identified as male, three who identified as queer

²³ World Bank (2019). *Kenya digital economy assessment*, p. 19.

<https://thedocs.worldbank.org/en/doc/3453416015906319580090022020/original/DE4AKenyasummarypaperfinal.pdf>

²⁴ Crenshaw, K.W., "On intersectionality: Essential writings" (2017). *Faculty Books*. 255. <https://scholarship.law.columbia.edu/books/255>

male, and one who identified as rainbow).²⁵ The queer men were fluent in English, owned smartphones, and said they protected sensitive communications on their phones by using passwords and hidden folders.

By contrast, the three female sex workers said that they used mobile phones predominantly to recruit clients, and that smartphones had become essential for this purpose. They described sharing smartphones with friends due to the cost, and the devastating impact on their collective livelihood if that phone was seized in a police raid. They described pressure from clients to share sensitive images and videos, and their trauma when those images were used by clients for extortion or public shaming. The women were unaware that their phones could also be used to access health information, and said that they would be unable to read it because they did not speak English.

In Ho Chi Minh City, HCM-FGD1-H5 summed up the view of many participants when he said that as a community volunteer during the Covid-19 crisis,

I realised that [health] apps are creating invisible injustice between people...because there are people who don't use smartphones, and those apps are creating distance for the poor who can't access basic needs.

Disclosures of harm

While participants overall expressed enthusiasm for using their mobile phones to access health information and support, some disclosed serious harms. Seventy percent of women across the study described harms, as did a majority of participants who identified as transgender or nonbinary. The harms included misdiagnosis, censorship, verbal abuse, threats and extortion, and physical violence. Seventy percent of women in all three countries described stalking and sexual harassment experienced by themselves or peers.

The reliance by many participants on Google and social media as a primary source of health information created challenges in navigating conflicting information. In digital ethnography, we documented numerous instances of misinformation, including accounts falsely offering “cures” for HIV.

Vietnamese participants and interviewees especially emphasised health misinformation as a concern. In Hanoi, a technology social entrepreneur, HAN-KII-H, said that some young people see misinformation on social media saying falsely

That a fever or a rash means HIV infection, [and] they become confused and go to test everywhere. Even though the test result is negative, they still believe the result is not true. Currently on the internet there are many websites that give false information.

A community doctor in Hanoi, HAN-KII-P, said,

In my opinion, many people have access to wrong information, and incorrect information will greatly affect their psychology as well as their treatment process. They start to feel confused and will go to many clinics for treatment, resulting in loss of money and time.

Conversely, participants also reported censorship of accurate SRH information on Facebook. In Nairobi, NBO-FGD1-N2 said that his posts accurately explaining how to use condoms led to repeated blocks of his account by Facebook: “I experienced being locked out of Facebook twice, and that has made me stop sharing the same on Facebook.” Others reported similar problems

²⁵ For the purpose of this report, we have used "queer male", "rainbow", "transgender" and other identifications as they were shared with us by study participants. Our consortium acknowledges that nuances of language are important, that we are applying an intersectional analysis and an anti-oppressive approach to our research, and that moving away from being heteronormative in our language while also being precise is an ongoing learning process for us.

with Facebook, and said that as a result they had switched to using other platforms, such as Twitter.

The research team for this study documented numerous instances of verbal abuse linked to health status, including on community health fora, where an apparently innocent question about a symptom could lead to mockery or denunciations by other forum members for promiscuity.

Seventy-three percent of young female participants in Kenya reported either personally experiencing or witnessing stigmatising verbal abuse, as did many young women in Ghana and Vietnam. The forms of verbal abuse they described were often sexualized.

In Kisumu, KSM-FGD4-K70 said,

One of my friends posted on Facebook that she feels cold, headache and what could be the problem? Just asking in *Kisumu Moms*. The things that she was told: “You are pregnant, you have sugar daddies,” and what and what. People started throwing words until she withdrew that post.

In Vietnam, several respondents shared that a young peer who spoke openly about living with HIV online had been widely denounced as sexually promiscuous on social media. Some described mental health harm as a result of verbal abuse. In Kisumu, KSM-FGD2-K47 said that when seeking health information and encountering only verbal abuse, “you will feel low at some point, it lowers the self-esteem of individuals.”

In some cases, the abuse turned threatening. In Nairobi, NBO-FGD1-N9 said,

I once championed against SGBV [sexual and gender-based violence]. They bullied me and they said that they will come for me. I was scared out of my mind... You have to be mentally strong.

Similarly, NBO-FGD1-N4 said that when she spoke out against sexual and gender-based violence (SGBV) online, “I remember someone who said that they were coming for me. I can’t lie, I was very scared.”

As noted above, Ghanaian sex workers described frequent threats by clients, including blackmail, extortion, and non-consensual exposure of their naked images on social media. They had not reported these abuses to the police out of fears it might expose them to arrest themselves, as sex work is criminalized. In Nairobi, NBO-FGD1-N9, a bar hostess, said that she sees young sex workers as especially vulnerable to this kind of abuse, but that due to their fears of arrest, “It is just something you have to deal with as an individual.”

In some cases, young people said, their participation in social chat groups and dating apps led to physical violence. In Ghana, gay men and other men who have sex with men said that their chat groups for HIV prevention work, the only space where they are currently able to meet, are at a constant risk of infiltration by homophobic individuals or groups. In several cases, they said, they or peers were lured into ambushes that led to beating, extortion, or sexual violence. In one instance, the attackers coerced a confession of homosexuality that was videotaped and shared on social media, as propaganda for a proposed anti-homosexuality bill.

None of those who participated in the study reported being able to access redress for harms. However, several said they still wanted redress, if only to deter others from abusive behavior.

Out of fear of verbal abuse and other harms, some respondents limit online participation. KSM-FGD2-K49 said she would not share information online:

I think taking my health to the digital platforms, especially social media, is a big “NO”. Because you will be cyberbullied, you will be misled, you are at risk of exposure.

In Vietnam, an HIV advocate we interviewed expressed concerns that these fears of online abuse and harm isolate individuals, cause mental health harm, and impede access to health information and services. In Tamale, TML-FGD2-C said that witnessing homophobic violence in person had led him to limit his searches online: “With these kinds of situations, if I wanted to search for LGBTI online, I would not.”

Dependence and surveillance

Participants described anxiety about dependence, especially in the context of concerns about surveillance.

When asked, “Do you control your phone, or does your phone control you?” many participants initially laughed. However, some then shared more serious observations, such as, “I am so addicted to my phone,” “Without my phone, I am nothing”, or “Without your phone, you don’t exist”. In Accra, ACC-FGD2-E said,

Sometimes, when I run out of data and I can’t find some, I feel so uncomfortable. I feel a part of me is dead, and I don’t know what is going around in the world.

Some focus group participants described dependence on phones as leading them to miss important appointments or university exams, and said it had increased their social anxiety. A few described efforts to reduce their dependence.

At the same time, focus group participants in Ghana and Kenya raised questions about surveillance by government agencies and private actors, domestically and internationally. They expressed a lack of clarity over how their data was processed and stored. In both Ghana and Kenya, participants shared instances in which political parties had apparently obtained their mobile phone numbers without consent. Some participants asked focus group discussion facilitators to explain “cookies” and advise whether or not to accept them.

In Kenya and Ghana, where abortion is restricted by law, young women asked focus group facilitators whether their searches for information about abortion could lead to either menstrual tracking apps or hostile organizations obtaining personal data and sharing it with the police.

Gaps in governance and participation by young adults

Given the many concerns outlined above, all three countries clearly need robust digital governance policies and strategies. Our review of laws, policies and strategies in Ghana, Kenya and Vietnam found that while important work is currently underway to develop digital strategies and policies, the issues documented above -- the risks of harms, the need for redress, and the digital divide -- do not appear to be on the digital governance agenda in any of the three countries. Experts in each country raised concerns about weak coordination and weak implementation of data protection. Young adults in all three countries called for a seat at the table in consultations and policy discussions and said they were keen to participate.

All three countries are in the process of developing new strategies and policies. The Ghanaian government was developing a major new digital strategy at the time of the study, though this did not appear to address the above concerns, or to engage young adults.²⁶ Ghana and Kenya already have national eHealth strategies, but these appear largely focused on health sector data management systems, and do not address mHealth, web searches, social media, or the other issues discussed in this report.²⁷ In Vietnam, our researchers found information on digital

²⁶ Dowuona, N. et. al. (2021). “A digitized Ghana: New technologies and innovation”. Blog. *Lexology*. <https://www.lexology.com/library/detail.aspx?g=13bef1f0-66b6-464b-8cb5-22eb799ea9af>.

²⁷ Kesse-Tachi, A., Asmah, A.E., and Agbozo E. (2019). “Factors influencing adoption of eHealth technologies in Ghana.” *Digital Health* 5 (January 1): 2055207619871425. <https://doi.org/10.1177/2055207619871425>; Preko, M., and Boateng, R. (2020). “Assessing healthcare digitalisation in Ghana: A critical realist’s approach.” *Health Policy and Technology* (9:2): 255–62. DOI: <https://doi.org/10.1016/j.hlpt.2020.03.006>; Ogoe, H.A., Asamani, J.A., Hochheiser, H., and Douglas, G. P. (2018) “Assessing Ghana’s eHealth workforce: Implications for planning and

governance challenging to obtain, but scholarly analyses have described governance of digital health as weak overall in Vietnam.²⁸

Both Ghana and Kenya have data protection laws and Data Protection Commissions. Vietnam's 2018 Cyber Security law has resulted in a 2021 Draft Decree on Personal Data Protection.²⁹ However, stakeholders we interviewed in all three countries described implementation as weak. In Nairobi, a key informant in the tech sector recalled poor government data protection during the Covid-19 pandemic. Speaking to the lack of public awareness, she recalled being required to give her biometric information in order to make a restaurant reservation.

Similarly, on Ghana's data protection law, a UN official in Accra (ACC-KII-B) said,

It's quite a clear, useful policy. Almost anybody that looks at it says that it's a world standard, [but]... My perception is there are still some gaps in implementation. It's not implemented as properly as it should [be].

In all three countries, key informants also called for better national coordination and quality control of proliferating mHealth apps. They pointed to the large number of mHealth pilots that have been launched by international organisations to public fanfare, and subsequently discarded when project funding ran out. In Vietnam, one UN official observed,

We have like two dozen kinds of [health] apps, but we are still struggling to have the one single app that works and is accepted by all the local authorities.

Given the preference of young adults for social media over mHealth apps, the UN official in Accra noted, health officials miss opportunities for more cost-effective health promotion when they give relatively little thought to strategic use of social media, where they could more easily reach young adults.

Young adults in all three countries expressed a strong desire to learn more about digital technologies and digital rights, and to have a voice in governance. "Meaningful inclusion, participation, that we are involved from the top level to the bottom level," said NBO-FGD4-N34. This was echoed by NBO-FGD4-N30, who said,

In most of the government offices, you find that people who are 60 years, 50 years old plus, are the ones speaking on behalf of young people. They don't know what we want. They assume they know what we want.

In Ho Chi Minh City, HCM-KII-L, a key populations community leader, agreed:

If young people use [an app], let them give their opinion. Learn from the experience of previous health applications that "died" because they did not meet the needs of [key populations] and no one used it.

When asked what policy recommendations they would make if they had a voice in policy-making, study participants urged universal access to airtime and health information; apps that link end users to trusted health providers for in-person consultation; stronger data protection; and more differentiated approaches to meet the health needs of "young people in our diversity".

training." *Human Resources for Health* (16:1): 65, DOI: <https://doi.org/10.1186/s12960-018-0330-8>; Mariwah, S., Abane, A.M., Owusu, S.A., et.al. (2021) "Formalising 'informal' mHealth in Ghana: Opportunities and challenges for Universal Health Coverage (UHC)." *Global Public Health*: 1–14, DOI:

<https://doi.org/10.1080/17441692.2021.1874467>; *Kenya National e-Health Strategy 2011-2017*, http://publications.universalhealth2030.org/uploads/kenyanation_ehealth_strategy.pdf

²⁸ Lam, J. et. al. (2018) "Mobile health Initiatives in Vietnam: Scoping study." *JMIR mHealth and uHealth*, (6:4): e106. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5941098/>

²⁹ D'Andrea and Partners (2021). "Vietnam's personal data protection: What is going to change?" Blog, 30 March. <https://www.dandreadpartners.com/draft-of-decree-on-personal-data-protection-in-vietnam/>.

Many underscored the importance of privacy. When asked what he wanted in an ideal mHealth app, one participant in Accra said he wants:

Nothing to trace back to me. Not even asking for my location, my country...I am nothing but a number or an emoji, and then I get the response I need. That's what I need.

Some young social media influencers also called for government health agencies to partner with them as health champions, training and certifying them as sources of health information for their peers. As NBO-FGD1-N20 suggested, “[If] you have been capacity-built and given the health information, maybe you can spread it to those people who don't have access to the internet or smart phones.”

Those who had experienced harm online also called for accountability and access to redress. When asked what form of justice she wanted, after describing the trauma of having her naked images shared to her community on Facebook without her consent, a sex worker in Accra (ACC-FGD3-A) said,

The way sex workers are always arrested and prosecuted -- can people who share other people's nude [images] be prosecuted and arrested as well? That is how sex workers can protect our data.

Despite the challenges and risks outlined above, young study participants in all three countries expressed a keen interest to learn more about digital apps and their legal rights, an interest to learn more about digital technologies and data, and an interest to participate in and contribute to policy discussions based on their experience.

Informants at both UN agencies and civil society groups expressed an interest to consult with young people and diverse communities in digital health. In Ghana, the UNAIDS country director described collaborating with medical students on their digital health initiative. UNAIDS in Vietnam described their close collaboration with key populations in the design of mHealth as having had a positive result on uptake and usability of the app.

While many officials we interviewed seemed unfamiliar with the extent to which young adults use social media platforms for health information, one WHO official in Ghana said he promotes WHO and its partners to engage in more strategic use of social media for targeted health promotion, because “if you want to reach young people, social media is where you will find them.”

In civil society, we found examples of projects and initiatives collaborating with young people effectively. A project manager at Savana Signatures, a Ghanaian NGO, described her close collaboration with young people in digital design:

Whatever we are doing that targets young people, we move with them. We move side by side. We actually let them take the lead. Then we'll provide the necessary guidance. Because they understand their situation much more than we do, let me put it that way.

DISCUSSION

As young people in Ghana, Kenya and Vietnam have come to increasingly rely on their mobile phones for access to health information, advice and support, we find they have experienced significant benefits, but also serious harms. Our findings highlight the intersectional nature of social and economic inequalities in shaping online access and skills.

The findings show the intersectional nature of what has been called the digital divide. Gender inequalities - including financial inclusion, gender roles, education, and security – play a significant role in shaping the digital experience of young women, other intersecting structural inequalities were also highlighted.³⁰ We noted that young women described themselves as especially keen seekers and users of health information online, who often enjoy sharing information with other peers and family members. Yet ironically, and unfortunately, they also described themselves as having less online access, less digital expertise, and facing greater risk of harm than did their male peers.

These inequalities were especially highlighted in the case of sex workers, for whom multiple inequalities intersected in ways that exposed them to harm, impeding their human right to physical and mental health and related rights to security and redress.

One of the starkest inequalities in the digital transformation appears to be the divide between the 'global North' and 'global South'. The health data of young people in low- and middle-income countries appears to be enriching technology companies in high-income countries, rather than LMIC health systems. In 2021, Flo, the fertility-tracking app we found in use in northern Ghana, settled a lawsuit by the U.S. Federal Trade Commission over sharing users' personal health data to Facebook (aka Meta) and Google.³¹ However, the lawsuit does not address how data may be governed or used beyond the U.S. borders.

The findings from this study demonstrate a need for governments to collaborate through the World Health Organization and other UN platforms to press for more robust regulation of social media and web platforms. The UN has an important role to play in highlighting positive innovations and working with countries to address harms and risks of harm. In 2021, WHO and UNDP both published guidance on the ethical and rights-based governance of digital health, which could be more widely disseminated and used at national levels.³²

Our findings also indicate remarkable grassroots innovation by young people in LMIC, many motivated by the public good. National governments may have a powerful untapped resource for addressing the imbalances of data colonialism, and promoting the right to health: young people. Young people have used their online access to information and social media networks to form extraordinarily powerful communities, investing little more than their own airtime and energy, and have literally saved lives by sharing medicines and information during Covid-19 lockdowns. As one young social media health champion suggested in Nairobi, they could do so much more by working together in partnership with health agencies.

³⁰ Storeng, K.T., Fukuda-Parr, S., Mahajan, M., and Venkatapuram, S. (2021) "Digital technology and the political determinants of health inequities: Special issue introduction." *Global Policy* (12: S6): 5–11. DOI: <https://doi.org/10.1111/1758-5899.13001>.

³¹ Federal Trade Commission (FTC) (2021). "FTC finalizes order with Flo Health, a fertility-tracking app that shared sensitive health data with Facebook, Google and others". Press statement, June 22. <https://www.ftc.gov/news-events/news/press-releases/2021/06/ftc-finalizes-order-flo-health-fertility-tracking-app-shared-sensitive-health-data-facebook-google>

³² UNDP (2021). *Guidance on the rights-based and ethical use of digital technologies in HIV and health programmes*. <https://www.undp.org/publications/guidance-rights-based-and-ethical-use-digital-technologies-hiv-and-health-programmes>; WHO (2021). *Ethics and governance of artificial intelligence for health*. <https://www.who.int/publications-detail-redirect/9789240029200>.

Future digital health strategies should engage young people in creative thinking about ways to bridge the intersectional digital divides, empower young people with knowledge and information, and consult them in the design and governance of digital technologies.

Our study suggests that transnational participatory action research may offer one effective approach to support this participation, locally and globally.

Strengths and limitations

The diversity of the research team, including people living with HIV and young adults from the three countries, constituted a significant strength, facilitating access to otherwise hard-to-access online spaces and communities. Through their established relationships of trust and their seasoned skills in consultation, the national researchers were able to facilitate disclosures of sensitive personal experiences.

Respondents were largely urban young adults connected to civil society networks, who thus do not constitute a representative sample of young people in the country.³³

The necessity to conduct online research in Vietnam during the Covid-19 pandemic, as well as sensitivities around the topic of digital rights, may have constrained the focus group discussions.

³³ Dedding, C., Goedhart, N.S., Broerse, J.E.W., et al. (2021). "Exploring the boundaries of 'good' Participatory Action Research in times of increasing popularity: dealing with constraints in local policy for digital inclusion. *Educational Action Research* 29: 20–36: <https://www.tandfonline.com/doi/full/10.1080/09650792.2020.1743733>.

CONCLUSIONS

National and global digital strategies and policies should uphold the right to access health information and services for all, and ensure equitable online access and a voice for young people in digital governance. Participatory action research offers one way to empower and engage young people in this process. Governments and health agencies should support grassroots online innovation by young health champions. National governments should also cooperate through UN platforms to demand more effective regulation of technology companies and ensure accountability for harms.

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THE RESEARCH TEAM

Elsie Ayeh has served as National President of the Ghana Network of Persons Living with HIV (NAP+ Ghana) since her election in September 2020. She has over 30 years' experience in designing, implementing, managing, monitoring and evaluating programmes and projects for rural and community development, farming systems research, gender and health, sexual and reproductive health including HIV, and savings mobilization for rural women.

Dong Do Dang was diagnosed with HIV in 1999 and has been working in the HIV field since 2005. He worked with one of the first PLHIV groups in Vietnam when he joined the HIV community. He was a member of the Foundation Board of VNP+ when the network formed in 2008. Currently, Dong is the Chairperson of VNP+ and the Executive Director of Action Center for People Living with HIV. He has conducted extensive quantitative and qualitative research in this role.

Sara (Meg) Davis, Ph.D. is Principal Investigator of the Digital Health and Rights Project, and Senior Researcher at the Global Health Centre, Geneva Graduate Institute. She earned her Ph.D. at the University of Pennsylvania. She was founding executive director of Asia Catalyst, and the first senior human rights advisor at the Global Fund. She is the author of two books: *The Uncounted: Politics of Data in Global Health* (Cambridge 2020) and *Song and Silence: Ethnic Revival on China's Southwest Borders* (Columbia 2005), as well as numerous reports and articles. Beginning June 2023, she will be Professor of Digital Health and Rights at University of Warwick.

Tabitha Ha is an Advocacy Manager at STOPAIDS. With over 10 years experience in national and global health policy and advocacy, she leads on STOPAIDS' advocacy around emerging digital technologies and their impact on human rights and coordinates the consortium's global advocacy work. She also supports the work of the Global Fund to Fight AIDS, TB and Malaria, as a member of the Developed Country NGO Board Delegation. In previous roles, she has worked at Oxfam and Restless Development, and also as an independent advisor.

Tara Imalingat is a lawyer and a health and human rights advocate at KELIN Kenya. She holds an LLB and a post-graduate diploma in Healthcare, Ethics and Law from the University of Manchester. She has a keen interest in research and advocacy towards the fulfilment of the right to health for all.

Irene Kpodo is a member of the National Association of People Living with HIV in Ghana (NAP+ Ghana) as an Administrator on a voluntary basis while doubling up as the Secretary to the Advisory Board of NAP+ Ghana. She is a facilitator of learning for diverse groups and communities. In her quest to address gaps in reaching adolescents and young PLHIV, she runs a small non-profit organisation aimed at transforming lives and impacting livelihoods.

Kaitlin Large is a Research Officer at the Global Health Centre, with the New Business Models for Governing Innovation and Global Access to Medicines research project. She holds a Master's degree in Development Studies from the Geneva Graduate Institute, and a Bachelor's degree in Global Studies with a minor in Professional Writing from the University of California, Santa Barbara

Nomtika Mjwana is a health advocacy & communications practitioner, with experience in HIV and sexual & reproductive justice programmes. She is currently working as a Project Manager for Digital Health Rights at the Global Network of People Living with HIV (GNP+).

Alex K. Muthui has over 12 years of experience conducting project evaluations and impact assessments in Kenya, Haiti, South Sudan, Somalia, Ethiopia, Tunisia, Cameroon, Mozambique, South Africa, Togo, Uganda, Kenya and Tanzania. He is certified in participatory M&E, and has consulted for non-profit and international organisations throughout Africa. He has led numerous research studies and reported on a wide variety of thematic areas, including: health-related rights, child protection and safeguarding, child rights governance, violence against women and girls, health sector assessments, education evaluations, labour market assessments, youth and women economic empowerment, vocational skills training, gender-based violence, civil rights and freedoms, peace and security, among others. He holds a Masters in Monitoring and Evaluation and is currently undertaking his Ph.D. thesis in Population Studies.

Pham Huyen Trang is an activist with 6 years of experience working in youth NGOs, child-related fields and gender equality, and now works as a project officer for a network of people living in Vietnam (VNP+). Her main job is to advocate for policies to ensure the rights of people living with HIV and to improve their understanding of their rights. She considers herself to be a passionate community servant with the ability to motivate and inspire individuals. With this ongoing quest to give, she has been able to promote significant, positive change in communities and individuals through advocacy, empowered by compassion. She takes pride in engaging in community-building as she committed to a life-long service based on personal and professional experiences.

Tony Sandset is a Research Fellow at the Centre for Sustainable Healthcare Education (SHE) at the Faculty of Medicine, University of Oslo. His current research focuses on knowledge translation within the field of HIV care and prevention. Specifically, his focus is on how medical knowledge from randomised controlled trials is mediated, how evidence is generated in HIV prevention, and how new medical technologies inform subjectivities, desire, and sexuality. Recent publications and research areas have been sustainable health care within sexual health, HIV prevention, and a focus on how evidence is made and used in support of sustainability.

Nerima Akinyi Were is an LLB and LLM graduate from the University of Pretoria. She has worked as a researcher at the Constitutional Court and the Land Claims Court, South Africa. She joined KELIN as a volunteer, becoming a pro-bono lawyer, program officer and manager for the Sexual and Reproductive Health and Rights thematic area. Nerima is now Deputy Executive Director at KELIN. She is a tutorial fellow at the University of Nairobi where she is pursuing her Ph.D. She was admitted to the Bar in 2017 and was a Mandela Washington Fellow in civic leadership at the Presidential Precinct, the University of Virginia, The College of William and Mary, James Monroe's Highland, James Madison's Montpelier and Thomas Jefferson's Monticello.



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