Digital health and human rights of young adults in Ghana, Kenya and Vietnam: a qualitative participatory action research study

Sara L M Davis [1], Trang Pham,[2] Irene Kpodo,[3] Tara Imalingat,[4]
Alex Kilonzo Muthui,[5] Nomtika Mjwana,[6] Tony Sandset,[7] Elsie Ayeh,[3]
Do Dang Dong,[2] Kaitlin Large,[8] Cedric Nininahazwe,[9] Timothy Wafula,[4]
Nerima Were,[4] Mike Podmore,[10] Allan Maleche,[4] Georgina Caswell[6]

For numbered affiliations see end of article.

Correspondence to
Dr Sara L M Davis;
sara.davis@graduateinstitute.ch

ABSTRACT

Introduction Digital health offers the potential to strengthen health systems in low- and middle-income countries. However, experts have warned about threats to human rights.

Methods We used qualitative methods to investigate how young adults in Ghana, Kenya and Vietnam use their mobile phones to access online health information and peer support, and what they see as the effect on their human rights. We applied a transnational participatory action research approach. Global and national networks of people living with HIV, AIDS activists, young adults and human rights lawyers participated in study design, desk review, digital ethnography, focus group discussions, key informant interviews and qualitative analysis.

Results We interviewed 174 young adults ages 18–30 in 24 focus groups in 7 cities in Ghana, Kenya and Vietnam, and held 36 key informant interviews with national and international stakeholders. Young adults reported predominantly using Google, social media and social chat groups for health information. They emphasised reliance on trusted peer networks, and the role of social media health champions. However, gender inequalities, class, education and geography create barriers to online access. Young adults also disclosed harms linked to seeking health information online. Some described anxiety about phone dependence and risk of surveillance. They called for a greater voice in digital governance.

Conclusion National health officials should invest in young adults' digital empowerment, and engage them in policy to address benefits and risks of digital health. Governments should cooperate to demand regulation of social media and web platforms to uphold the right to health.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Digital health has boomed during the COVID-19 pandemic.
⇒ Global health agencies promote digitisation in low-income and middle-income countries in order to reach the Sustainable Development Goal on health.
⇒ Human rights scholars have raised concerns about data colonialism, unequal access, and threats to privacy, equality, and autonomy.

WHAT THIS STUDY ADDS

⇒ Young adults report using Google, social media and social chat groups as a primary source of health information on their phones, rather than mHealth applications.
⇒ While social media creates risk of misinformation and misdiagnosis, peer-led networks and social media health champions also play an important role in accessing accurate health information and peer support.
⇒ Digital access and risks of harm are shaped by inequalities such as class, education, gender, language, disability and geographical location.
⇒ Young adults reported harms linked to seeking and sharing health information including censorship, verbal abuse and violence.
⇒ Many expressed anxiety about risk of surveillance, and a strong interest in learning about digital rights and in having a voice in policy.

INTRODUCTION

'Digital health' is defined by the WHO as describing digital technologies used for health promotion, service delivery, supply chain management, financing, human resource management and data services.[1]

United Nations (UN) agencies have actively promoted the use of digital technologies and artificial intelligence in order to accelerate progress towards the Sustainable Development Goals. In 2020, the World Health Assembly approved a Global Strategy on Digital Health 2020–2025, committing member states to implementing national digital health strategies.[2]

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ National and global digital strategies and policies should promote young adults' right to access sexual and reproductive health information, and ensure equitable online access.
⇒ Governments should demand more effective regulation of tech companies in high-income countries, protecting data on young adults' health and using it to strengthen local health systems, and support innovation by young adults online.
⇒ Participatory action research offers one way to empower and engage young adults in digital health governance.

In promoting digitisation, UN and development agencies have noted the challenges posed by gender inequalities: fewer young women than men have access to the internet, and women are under-represented in tech design and management. In Ghana, over 2.5 million fewer women are online than men.[3]

However, these agencies have yet to address numerous other human rights risks linked to digitisation. UN human rights experts have raised concerns including threats to privacy, and the privatisation of welfare services.[4–7] They have cautioned that algorithmic biases amplify racial discrimination, and warned of risk of online violence, including cyberbullying.[8 9]

Surveys have found that many adults in low-income and middle-income countries (LMICs) own or have access to mobile phones, and that most of those with access to smartphones also use social media and other online platforms.[10] A growing number of mobile phone users in LMICs rely on them to access health information and services.[11]

However, mobile phone applications are often intentionally designed to encourage high rates of user engagement.[12] This enables both longer-term user retention, and extraction of personal data for sale to third parties, or for product development.[13] High rates of user engagement may cause other harms: problematic cell phone use, aka 'phone addiction', may negatively impact on mental health.[14] The data of young adults also offers insights into future consumer trends. Thus, young adults are vulnerable to targeting for increased engagement.[15] Scholars have raised concerns that such forms of data extraction constitute a new form of colonialism.[16]

Given these concerns, and the growing investment in digital health by health agencies, we identified a need for empirical evidence of the positive and negative effects of the digital transformation on health-related human rights of young adults in LMICs to inform policy. The cofounders of our research consortium include the leaders of civil society and community networks who play governance and advisory roles in global health governance agencies and social scientists. We established the Digital Health and Rights Project consortium including anthropologists at Geneva Graduate Institute (Switzerland), BRAC University (Bangladesh), Universidad de los Andes (Colombia) and University of Oslo (Norway);

human rights lawyers at the Kenya Legal & Ethical Issues Network on HIV and AIDS, KELIN (Kenya); health advocates at STOPAIDS (UK); the Global Network of People Living with HIV (GNP+), which mobilises and represents national and regional networks and organisations of people living with HIV (PLHIV); and national member networks of GNP+.

This study aimed to investigate how young adults in Ghana, Kenya and Vietnam use mobile phones to access online HIV, sexual and reproductive health (SRH), and COVID-19 information and services; what young adults themselves identify as the benefits and risks to their human rights of the digital transformation of health; and their role, if any, in shaping the digital health agenda. We aimed to engage a diverse population of young adults, including both young adults from the general population, and marginalised communities—including young adults living with HIV and 'key populations' vulnerable to HIV (gay men and other men who have sex with men, transgender people, sex workers and people who use drugs). We aimed to draw on this research and the recommendations of these diverse young adults to influence global health governance.[17]

Our approach references human right standards grounded in international law, as a significant body of research has established that punitive laws and related discrimination impact on health service access and uptake, including for women, PLHIV and key populations.[18] The Joint UN Programme on HIV and AIDS (UNAIDS) has noted that 134 countries criminalise or prosecute HIV exposure; 20 countries criminalise or prosecute transgender persons; 153 countries criminalise sex work and 67 countries now criminalise same-sex sexual behaviour; and UNAIDS has warned that these laws and practices create barriers to health services for those who need them most.[19] This has been shown, for instance, in Nigeria, where one study of HIV service uptake found that a cohort of men who have sex with men had less access those services immediately after the enactment of the Same-Sex Marriage Prohibition Act.[20] Similarly, fear, stigma and denial related to SRH have undermined access to SRH services, for instance, for sex workers.[21]

METHODS

Participatory action research approach

To address underlying power imbalances, and to build capacity in national and global organisations and networks to advocate on these issues long term, we 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.[22] Studies have found that PAR increases applicability of findings and builds long-term ownership of health interventions.[23 24] The PAR approach is consistent with a growing demand for citizen science in global health, and with commitments by UN

member states to increase public participation in health data gathering.[25]

There is no one-size-fits-all normative model of PAR, and methods vary to fit diverse contexts. Core elements of this approach generally include the central role of researchers from the affected community under study, who also facilitate wider engagement by their peers; verification of findings by consensual validation of study participants; and the use of resulting knowledge by community members and others to promote change.[26] Campbell and Murray argue that the process of participatory research aids in raising a group's awareness of their unequal situation, and of the challenges to be overcome to create change.[27]

PAR has largely been done at local levels. This study is one of the first to apply PAR transnationally, by building on the global and national infrastructure put in place by communities of PLHIV. Thus, it may be helpful to elaborate the approach we developed to apply PAR in three settings.

First, the consortium established an international steering committee, comprising the principal investigator (PI) at the Graduate Institute, and senior managers from each organisation or network. The steering committee oversees the project, meeting via videoconference each month, with a rotating chair. The project was therefore overseen in part by GNP+, a global network whose mission is to represent the voices of PLHIV in international platforms, and by KELIN, a Kenyan human rights group.

Second, we involved early-career national researchers from the communities under study (young adults ages 18–30, including PLHIV; and lesbian, gay, bisexual, transgender, intersex and queer (LGBTIQ+) people). The research team included the PI, a postdoctoral researcher, research assistant and early-career researchers at national organisations in each country (ie, the Ghana Network of Persons Living with HIV [NAP+Ghana], the Vietnamese Network of People Living with HIV [VNP+] and KELIN in Kenya). (We have opted for LGBTIQ+ here as the most inclusive abbreviation, noting that study participants sometimes used LGBT, LGBTQ or other abbreviations.)

This research team collaborated through weekly videoconference calls in study design, ethics and methods training, data-gathering and analysis. The national organisations applied for and obtained ethical approval in each country, and national researchers participated in field research exchanges between Kenya and Ghana, providing peer support. The full consortium approved the protocol, tools and analysis by consensus. A project advisory committee, including two youth advocates, advised the project throughout.

Third, the national researchers also presented the findings, including policy recommendations, to the study participants in each country for validation by consensus. The feedback from these sessions was reviewed by the full consortium at an in-person workshop in Nairobi.

The fourth aspect of transnational PAR was a consortium-wide advocacy strategy and an advocacy working group, led by STOPAIDS. This working group met monthly online to coordinate ongoing engagement at national and international agencies. GNP+ led a group that used the research findings to develop digital literacy training materials that are being used in the three countries to train young PLHIV and key populations on their rights. The full consortium collaborated with STOPAIDS to develop and publish a policy brief and held a series of online webinars including presentations by national researchers.

At the national level, national organisations used the study findings and recommendations in their ongoing engagement with national health processes. In Vietnam, for example, VNP+ presented the study findings to national and bilateral aid agencies and successfully influenced national HIV funding plans.

Design

The consortium steering committee identified the three focus countries based in part on the interest and engagement of national organisations. Ghana, Kenya and Vietnam were further selected as they exemplify diverse stages of digital transformation in three geographical 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 as some individuals own multiple phones. In Vietnam, over 80% of the population over 15 years of age now owns a smartphone.[28] Each country also has different HIV epidemics: Kenya has highest prevalence, while Vietnam's epidemic is concentrated among young key populations.

Our qualitative methods included comparative review of laws and policies, digital ethnography, focus group discussions (FGDs) and key informant interviews (KIIs), as discussed below. We used the Standards for Reporting Qualitative Research guidelines, a standard for formulating and reporting on qualitative research.[29] We used three methodologies to inform our analysis of the data emerging from the FGDs with young adults, as follows:

1. Law and policy review: To understand the context of digitisation, we reviewed laws, policies and strategies on digital governance and health in Ghana, Kenya and Vietnam; international human rights standards and relevant court judgements.[30 31] This enabled us to form a collective analysis and to identify core concepts that were applied in the analysis.

2. Digital ethnography: To explore how young adults use digital spaces to gather health information, researchers conducted participant observation in health-related web sites, social media accounts and social chat groups (eg, WhatsApp) in each country with active youth engagement, focusing on sites with higher rates of engagement. The digital ethnography informed our understanding of the specific ways in which young adults use online

platforms for health, the tensions in their exploration of sensitive health issues in those spaces, and some of the benefits and risks they encounter.

3. KIIs—SLMD, TI, IK, AKM, NM, NW and TP conducted semistructured interviews to gain expert perspectives on the opportunities and challenges posed by the digital transformation of health in each country, and to help us in framing policy recommendations based on the FGDs. We created a common list of institutions to reach out to in all three countries for KIIs, which included UNAIDS, the UN Development Programme, WHO, the US President's Emergency Plan for AIDS Response; national and regional health officials; managers and technical staff of non-governmental organisations (NGOs) and private sector companies; community health workers; and leaders of community networks of young adults living with HIV and key populations. We aimed to conduct approximately 8–10 KIIs in each country, and recruited interviewees based on established contacts of the research team and project advisory committee. Interview questions focused on trends in digital health governance, benefits and risks of digitisation, barriers to access and policy recommendations.

Taken together, these three methodologies helped us to formulate the questions for the FGDs, to fine-tune our understanding of digital health governance in each country, and to analyse the data that resulted from the FGDs.

FGDs: To probe the issues in more depth and develop policy recommendations, we organised 24 FGDs with diverse young adults ages 18–30.

The age range was set by the consortium, based on the definition of 'young people' used in global youth-led networks with which consortium member organisations collaborate. The younger limit was set to ensure recruitment of participants with the right to consent to online access and to access health services. The study population included diverse young adults; women, men, transgender and non-binary people, including PLHIV and young key populations (sex workers, people who use drugs and LGBTQ+ people). This diversity was emphasised as an important value by the participants in the study, who urged us to recognise and include 'young people in our diversity'.

We held eight FGDs in Ghana (four in Accra, two in Kumasi, two in Tamale), eight focus groups in Kenya (four in Nairobi, four in Kisumu) and six focus groups in Vietnam (one in Ho Chi Minh City, five in Hanoi) between October 2021 and February 2022. Due to COVID-19 restrictions, Vietnam FGDs were conducted via video conference.

Each focus group had 6–10 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. Each national team made minor adaptations to the discussion guide in consultation with the PI to fit local contexts. FGDs were led by SLMD, TI, AKM, IK or TP and lasted 90–120 min. Participants received travel subsidies and snacks.

Recruitment—Researchers used 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. Recruitment ended on reaching sampling saturation.

Ethical issues—Ethical risks in this study relate to the participation of young adults whose identities are stigmatised (eg, HIV status, sexual orientation, gender identity), or engagement by some participants in behaviours (such as abortion, sex work, same-sex sexual behaviour) that may be criminalised.[32] A further risk was that key informants or young participants might express views critical of the government, and experience retaliation. In Vietnam, working on human rights entails political risks.

Participants were not asked to disclose sensitive information including HIV status or sexual orientation, and those who volunteered it in the course of the research were reassured that their comments were anonymised. Those disclosing harm were followed up with separately and provided with links to supportive services. Informed consent procedures were followed, and data were anonymised using codes. Protective measures were taken with regard to the transfer of data and sharing of data among partners. In Vietnam, our national partner advised on measures to avoid political risks, including careful use of language.

Analysis—National organisations transcribed transcripts, and translated them into English where necessary. Two researchers reviewed each transcript (AKM, TS, TI, IK, KL and SLMD). Four researchers (SLMD, AKM, TS and KL) conducted thematic analysis of the FGD transcripts using Dedoose, and coded 10 sample transcripts across the 3 countries inductively. The codebook was refined using human rights concepts identified in the desk review. The full consortium finalised the codebook. Each transcript was coded by one coder; a selection was reviewed by a second coder.

Given the smaller number of KIIs and their diverse membership and subject expertise, we determined that coding analysis would not identify useful patterns. Rather, we drew on the KIIs in drafting policy recommendations related to digital health governance. Key informants also participated in the validation meetings to provide feedback on the draft policy recommendations and advised on opportunities to disseminate them at national and international levels.

Validation—In each country, national researchers presented the draft findings and recommendations to study participants for discussion in a videoconference call. Their input was shared with the full consortium at an in-person workshop in Nairobi, as part of the process of (A) collectively finalising the overall study findings for this article and (B) collectively finalising the policy recommendations for use in our policy brief.

Table 1	Key informant interviewee occupations
Kenya	Executive director/digital marketer
	Sex educator/blogger/vlogger
	NGO country director/clinical director
	Chief executive officer, tech company
	Country director, UN agency
	Head of digital health professional association
Ghana	Country director and country directors, UN agency
	Advocacy focal point, international NGO
	Manager, telemedicine centre, international NGO
	Executive director, community-based NGO
	Technical advisors, bilateral aid agency
	National specialist, UN agency
	Peer outreach workers, national NGO
	Regional HIV coordinator, national agency
	Programme manager, national NGO
	National president, youth health network
Vietnam	Health advisors, UN agencies
	Community leaders, PLHIV networks
	Key populations and NGO community leaders
	Founders of social enterprises
	Medical doctor

NGO, non-governmental organisation; PLHIV, people living with HIV; UN, United Nation.

Table 2	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**

FGD, focus group discussion.

Patient and public involvement—The study was designed in collaboration with national and global networks of PLHIV, including young adults. National networks of PLHIV and human rights lawyers coordinated the study in each country, and young staff participated as researchers. The findings and draft recommendations were discussed with study participants for validation. Participants were also invited to join national and international online events to disseminate the findings.

A reflexivity statement is included in online supplemental appendix S1.

RESULTS
Sample
A total of 36 people participated in KIIs, including 6 people in Kenya, 15 in Vietnam and 15 in Ghana. We did not request gender, age or other demographic information from the KII participants. Their occupations are listed in table 1.

A total of 181 young adults participated in FGDs. After excluding those non-eligible due to age, participants included 174 young adults, ages 18–30: 56 in Ghana, 71 in Kenya and 47 in Vietnam (table 2).

Figure 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.

For the purposes of this report, we have used 'queer male', 'rainbow', 'transgender' and other identifications as shared by participants. Our consortium acknowledges that nuances of language are important, that we are applying an intersectional analysis and an antioppressive approach to our research, and that shifting from linguistic heteronormativity while retaining precision constitutes an ongoing learning process for us.

Most participants in all three countries were between the ages of 22 and 27. In terms of occupation, they 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.

Accessing digital health: preference for social media
Most participants in all three countries confirmed that smartphones were their main portal for online health information, and many reported relying on web searches (especially Google), social media (Facebook, Twitter, YouTube, TikTok, Instagram) and social chat apps (WhatsApp or Zalo in Vietnam) for health information and advice. A smaller number, predominantly young female university students, described using mHealth apps, such as menstrual tracking apps or pregnancy apps. We found Flo, a British app for period cycle tracking, widely in use in even remote regions, such as Tamale in northern Ghana.

Kenya, Vietnam, Ghana
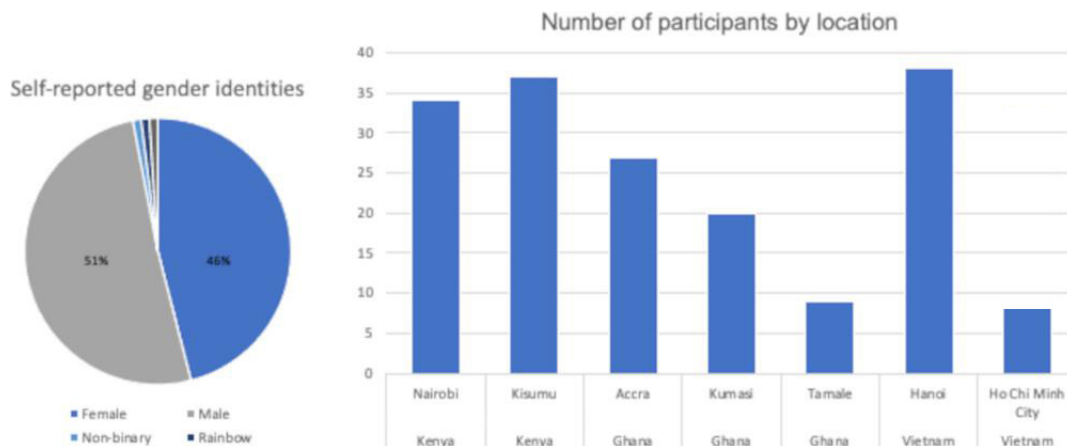
Figure 1 Focus group discussion participants by gender identity and location.

In all three countries, participants said they had experienced stigma when seeking advice in person at clinics, and thus felt safer seeking it online. For example, in Tamale, TML-FGD1-C described leaving a hospital without completing her HIV test after meeting a judgemental healthcare worker. In Kisumu, KSM-FGD4-K70 described sexual harassment by her doctor, which led her to avoid him. Others said that asking for SRH or HIV information at clinics could lead to being judged as 'irresponsible and immoral'. In Accra, two young men who identified as queer males expressed concerns that Ghana's proposed antihomosexuality bill would lead to the Ghana Health Service using coercive conversion therapy.

Young adults with smartphones described feeling empowered and knowledgeable when they could freely access health information and share it with others. For example, in Kisumu, KSM-FGD3-K55 said,

> I think I could have become a doctor during this Covid period [*laughs*] …During that Covid period 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.

Self-diagnosis on Google also led to concerns about misdiagnosis, discussed further below. However, overall young adults described digital health as beneficial and called for their governments to develop it further.

Social media health champions, safe space and 'online family'

We documented numerous grassroots innovations responding to the demand from young adults for online access to health information, especially during COVID-19 restrictions. These ranged from social media accounts with tens or hundreds of thousands of followers, to small peer-led social chat groups.

One larger account is Love Matters Kenya, a Facebook group with over 1.8 million members (https://www.facebook.com/LoveMattersAfrica/). The site shares information on SRH, promoting debate on related topics. Also in Kenya, NBO-KII-B, an Instagram influencer with over 30 000 followers, described consulting researchers and health experts to answer SRHR questions from her followers. In Vietnam, HCM-KII-D described sharing information on HIV testing and pre-exposure prophylaxis with over 20 000 YouTube followers. These social media health champions emphasised the importance of empathy, personal sharing, youth-friendly images and careful moderation of comments to create 'safe spaces'.

We also documented smaller, community-led initiatives. In Nairobi, NBO-FGD1-N1 described losing his cousin to suicide and seeing another friend struggle with teen pregnancy. As a result, he said,

> 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 said he now regularly monitors government health websites and shares information with his social media followers. We documented numerous social chat groups where young adults exchange health information and support, on topics such as diabetes, nutrition and ectopic pregnancy. HIV peer outreach workers described using Facebook and WhatsApp groups to provide psychosocial support, treatment adherence advice and to coordinate emergency medical and financial aid during COVID-19 lockdowns.

In Vietnam, a researcher (TP) conducted digital ethnography in a Zalo chat group for young adults living with HIV, with their consent. She documented how peers helped one another with urgent medical and financial assistance. During COVID-19 travel restrictions, one group member reported finished a prescription for antiretroviral medications, and told the group she was afraid to request permission to travel to the clinic, as this

would require disclosing her HIV status to local officials. Peers in the Zalo group privately delivered the refills to her.

Some social chat group coordinators described a formal agenda for these discussions. In Nairobi, NBO-FGD3-N25 said that a young person leads her WhatsApp group, and invites clinicians in for scheduled chat sessions on HIV or TB. In Ghana, young men who have sex with men who lead HIV peer outreach groups said that given widespread homophobic violence and recent police raids, these social chat groups had become the only safe means for their community to gather. KSI-KII-ABC 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.

Intersectionality and the digital divide

Given the important role of social chat groups and other networks in providing access to health information and psychosocial support, online access has become increasingly crucial for young adults. Participants shared concerns about the digital gender divide, and other structural inequalities that shape access to smartphones. These included socioeconomic class, language, disability and rural/urban divides.[33]

Many participants raised concerns about the high cost of airtime; in particular, women and transgender participants in smaller cities. Several recalled wanting to search for health information online when they could not, because they lacked the funds to pay for airtime. Others described having to share mobile phones with family members. Several highlighted the importance of toll-free hotlines and text message services run by national agencies and groups.

Language was frequently cited as a barrier, because all three countries are linguistically diverse, yet 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.[34] The intersectional nature of the digital divide was particularly clear in one FGD in Accra with one group of 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 male, and one who identified as rainbow). The latter group was fluent in English, owned smartphones, and had the digital sophistication to protect sensitive communications by using password-protected folders.

By contrast, the female sex workers described sharing smartphones with peers to save money, relying on smartphones to recruit clients, and trauma caused by public shaming or violence when clients shared their sexualised images on social media without consent. The sex workers

were unaware that their smartphones could also be used to access health information, and said that they would be unable to read it in any case, because they did not read 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 realized 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.

Participants urged greater consideration of the diverse digital health needs of young adults, including rural young adults and young people with disabilities. They called for more action by governments to address the digital gender divide and other digital divides. Several participants in Kenya and Ghana called for free or low-cost airtime to facilitate access to digital health.

Disclosures of harm

Some participants also disclosed serious harms in the process of seeking health information and advice online. Seventy per cent of women across the study described harms to themselves or peers, as did a majority of transgender or non-binary participants. The harms included misdiagnosis, censorship, verbal abuse, threats and extortion, and physical violence. Seventy per cent of women also 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, which some said created anxiety. In digital ethnography, we documented numerous instances of misinformation, including accounts falsely offering 'cures' for HIV.

Vietnamese FGD participants especially emphasised misinformation as a concern and called for greater regulation of health misinformation, including fake cures, promoted on social media. A community doctor, 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.

Participants also reported censorship of accurate SRH information. In Nairobi, NBO-FGD1-N2 said his Facebook posts explaining how to use condoms had been censored: 'I experienced being locked out of Facebook twice, and that has made me stop sharing the same on Facebook.'

A majority of women described verbal abuse. In Kenya, 73% of young female participants reported either personally experiencing or witnessing cyberbullying. The verbal abuse was often sexualised. 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 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.

Seventy per cent of women in all three countries discussed experiencing sexual harassment. Ghanaian sex workers described blackmail, extortion and fears that reporting these abuses to the police would lead to their own arrest, as sex work is criminalised. In Nairobi, NBO-FGD1-N9, a bar hostess, said that because of criminalisation, 'It is just something you have to deal with as an individual.'

In Ghana, gay men and other men who have sex with men described violent harms linked to their HIV prevention work online. In several cases, they or peers were lured into ambushes that led to beating, extortion or sexual violence. In one instance, attackers coerced a confession of homosexuality that was videotaped and shared on social media, as propaganda for the antihomosexuality bill.

As a result, some respondents said they limit online participation. In Tamale, TML-FGD2-C said that after witnessing violent threats against a gay friend: 'Even if I wanted to search for LGBTI online, I would not.' In Vietnam, an HIV advocate expressed concerns that such fears isolate young adults, cause mental health harms, and impede access to health information. Some FGD participants called for accountability for these harms, and for police to develop awareness about and act to address online abuse.

Surveillance, dependence and control

Perhaps unsurprisingly, given the mix of benefits and harms reported above, participants described a complex relationship of mobile phone dependence and avoidance. Many described feeling dependent, saying, 'I am so addicted to my phone,' or 'Without your phone, you don't exist'. For some, this led to depression and social isolation. 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.

A few described individual efforts to reduce their dependence.

While a small number of participants in each country were sophisticated users and designers of apps, most participants did not know how their data were used or governed. Several discussion facilitators had to explain 'cookies' and whether participants should accept them. Some expressed concern about risk of surveillance and manipulation by private companies in high-income countries, such as Google. Others suggested that their use of mobile phones could be surveilled by the police in their own countries, or by foreign governments, such as the USA. In Kenya and Ghana, where abortion is restricted,

some young women worried whether their searches for information about abortion could lead to hostile organisations or the police targeting them.

Many participants underscored the importance of privacy and strong data protection. This was especially true for women, young people who identified as LGBTQ+, and young people who identified as living with HIV. When asked for suggestions for an ideal digital health app, ACC-FGD2-E 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.

However, FGD participants were generally sceptical about the effectiveness of existing measures in protecting their privacy and data security and called for more effective data protection regimes.

Governance and youth participation

Our review of laws, policies and strategies in all three countries found weak regulation of digital health. We found no evidence of young adults being consulted in digital health strategies or policies.

While the Ghanaian government was launching a new digital strategy at the time of the study, this did not appear to address health or to regulate privacy, data extraction, redress for harms or other concerns raised by young adults.[35] Ghana and Kenya have national eHealth strategies, but these do not address mHealth, web searches or social media.[36–39] Vietnam has a Cybersecurity Law, but analysts have described governance as weak.[40]

Both Ghana and Kenya have data protection laws and Data Protection Commissions. Vietnam has a 2021 Draft Decree on Personal Data Protection.[41] However, most participants were unaware of the content of these laws and policies, or their rights under them.

Focus group participants and key informants described a general lack of awareness of national data protection laws and practices of intrusive data-gathering, especially in the context of the COVID-19 response. UN officials described weak enforcement overall.

Key informants in all three countries raised concerns about coordination and quality control of the proliferation of mHealth app pilots. In Vietnam, HAN-KII-A, a 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, ACC-KII-B, a UN official in Ghana, noted that health officials miss opportunities for more cost-effective health promotion when they treat social media as a low-cost option and give relatively little thought to its strategic use, although social media is the place where they could easily reach young adults.

Youth participation in strategies and policies

Informants at both UN agencies and civil society groups expressed an interest to consult with young adults and diverse communities in digital health, and in some cases, we documented pilot projects led by UN agencies and NGOs that appeared to be working closely with young people on digital design. TML-KII-B, a project manager at a Ghanaian NGO in Tamale, described her close collaboration with young adults in digital programme design:

> Whatever we are doing that targets young adults, 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.

Study participants in all three countries expressed a keen interest to learn more about digital health, technology and their legal rights, and an interest to contribute to policy. A participant in Vietnam said, 'I want the government to listen more…to young adults like us.' In Nairobi, NBO-FGD4-N34 called for 'Meaningful inclusion, participation, that we are involved from the top level to the bottom level.'

DISCUSSION

As young adults in Ghana, Kenya and Vietnam have come to increasingly rely on their mobile phones for many things, including access to health information and peer support, we find they have experienced significant benefits, as well as serious harms.

We noted that young adults, in particular young women, described themselves as especially keen seekers and users of health information online, in part because many fear being judged or stigmatised at in-person clinics. Digital platforms, in particular web search platforms and social media, have become central sources of health information and advice for young adults.

The findings show the intersectional nature of what has been called the digital gender divide. Gender inequalities—including financial inclusion, gender roles, education and security—seem to play a significant role in shaping the digital experience of young adults, and other intersecting structural inequalities were also highlighted.[42]

Participants also described significant harms, especially young women, key populations and PLHIV. They also described themselves as having less access, less digital expertise and facing greater risk of harm than their male peers. These inequalities were especially highlighted in the case of sex workers, for whom multiple inequalities intersected in ways that impede their human right to physical and mental health; as well as in the case of young gay men and other men who have sex with men in Ghana, who face risk of harm when gathering online.

The online world of social media, social chat and web searches where health information and peer advice is sought and provided appears to be virtually ungoverned, and is not addressed in the growing body of regulations and frameworks in Ghana, Kenya or Vietnam for planning and coordinating digital health. As a result, and as some young adults feared, the health data of young adults in LMICs may indeed be enriching social media and web search engines in high-income countries, rather than LMIC health systems. For example, Flo, the fertility-tracking app we found in use in northern Ghana, settled a lawsuit in 2021 by the US Federal Trade Commission over the unauthorised sharing of users' personal health data with Facebook (aka Meta) and Google.[43] The lawsuit did not address how data may be governed or used beyond the US borders.

The findings from this study demonstrate a need for governments to collaborate through the WHO and other UN platforms to press for more robust regulation of social media and web platforms, and to consult with and partner with young adults in LMICs in these discussions.

Young adults demonstrate remarkable grassroots innovation, many motivated by the public good, and an enthusiasm to learn and participate in the digital transformation. Young adults have used their online access to information and social media networks to form extraordinarily powerful communities, investing little more than their own time and airtime, and have literally saved lives by sharing medicines, information and emotional support during COVID-19 lockdowns. What could they achieve with meaningful investment and support?

Future digital health strategies and plans should engage diverse young adults in creative thinking about ways to bridge the intersectional digital divides, empower young adults with knowledge and information about their digital rights, and strengthen governance of digital technologies for health, including social media and web searches. Our study suggests that PAR may offer one route to lay the foundations for this approach.

Strengths and limitations

Using a PAR approach, the research team was able to get access to otherwise inaccessible online spaces and marginalised young adults, and to apply the research findings in national policy discussions. However, respondents were largely educated, and connected to civil society networks. Thus, many were socially engaged or themselves members of marginalised groups and did not represent a representative sample in each country, as can frequently be the case in participatory studies.[44]

The study was conducted in urban areas and did not explore the needs and concerns of young adults in peri-urban and rural areas of the three countries. Further research is needed to investigate a more diverse sample of young adults in all three countries.

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 adults in digital governance. PAR offers one

way to empower and engage young adults in this process. Governments and health agencies should support grassroots online innovation by young health champions. Governments in LMICs should also cooperate to demand more effective regulation of social media and web platforms for health, and ensure accountability for online harms.

Author affiliations

[1]Global Health Centre, Graduate Institute of International and Development Studies, Geneva, Switzerland

[2]Vietnam Network of People Living with HIV (VNP+), Hanoi, Viet Nam

[3]Ghana Network of Persons Living with HIV (NAP+ Ghana), Accra, Ghana

[4]KELIN, Nairobi, Kenya

[5]University of Nairobi, Nairobi, Kenya

[6]Global Network of People Living with HIV (GNP+), Cape Town, South Africa

[7]University of Oslo Faculty of Medicine, Oslo, Norway

[8]Graduate Institute of International and Development Studies, Geneve, Switzerland

[9]Global Network of People Living with HIV (GNP+), Amsterdam, The Netherlands

[10]STOPAIDS, London, UK

Twitter Sara L M Davis @saralmdavis and Nerima Were @nemowere

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Patient consent for publication Not applicable.

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ORCID iD

Sara L M Davis http://orcid.org/0000-0003-0914-3529

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Supplemental material

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Appendix S1 – Reflexivity statement

1. How does this study address local research and policy priorities?

The study was conceptualized by international and national civil society and community representatives of people living with and affected by HIV, working in collaboration with a social scientist in a high-income country (SLMD). The study aims to gather empirical realities on the digital transformation of health to inform policy recommendations. This is an issue of emerging concern for diverse young adults in low- and middle-income countries (LMICs), as well as for global health finance and governance agencies.

2. How were local researchers involved in study design?

As the process took place during the Covid-19 pandemic in 2020-21, we met through a regular schedule of videoconference calls to develop and conduct the study. We formed a global consortium including a steering committee with civil society managers and social scientists (including the Global Network of People Living with HIV, GNP+), and a research team including early career researchers from each country, supervised by the principal investigator.

In Kenya, the national partner was the Kenya Ethical and Legal Issues Network in HIV & AIDS (KELIN). In Ghana and Vietnam the national partners were the executive directors of the Ghana National Association of People Living with HIV (NAP+ Ghana) and the Vietnam Network of People Living with HIV (VNP+). Their participation in the study was facilitated and supported by GNP+. Each national organization applied for ethical approval in their own country, and identified a national researcher (TP, IK, AM and TI) to conduct the research with ongoing training and mentorship (from SLMD, TO and NM).

Thus both senior managers and local/junior researchers participated in study design from the outset through monthly and weekly videoconference calls, which are chaired by a different consortium member each time. The agenda for these meetings and all minutes are kept on a shared drive to which all consortium members have access.

Local researchers led workshops in each country to review and fine-tune the study instruments. Local researchers also recruited key informants and focus group discussion participants, drawing on their existing institutional networks. They were trained and mentored to conduct the interviews and focus group discussions, and exchanged advice with one another through the weekly consortium videoconference calls and through in-person field study exchanges in Ghana and Kenya.

3. How has funding been used to support the local research team?

All of the organizations in the consortium were joint applicants for a two-year grant from Fondation Botnar, and collaboratively co-authored the proposal and budget. The grant covered partial staff time for local researchers, senior managers and social scientists at the Geneva Graduate Institute. The Graduate Institute was the main grant recipient, coordinating timelines and reporting to the donor on behalf of the consortium.

4. How are research staff who conducted data collection acknowledged?

They are listed as co-authors. Some junior collaborators who participated more sporadically are acknowledged in the acknowledgements section.

5. Do all members of the research partnership have access to study data?

Yes. The consortium has signed a data management policy which clarifies that the data from each country is the property of the national organization. Data from any of the countries may be used by other consortium partners for publication, with written approval of the national organization. In Kenya, in compliance with the requirements of the ethical approval, data may only be shared with a signed data protection agreement.

6. How was data used to develop analytical skills within the partnership?

The data was used to develop analytical skills during the research process as follows: a) Researchers drafted inception papers based on desk review of laws and policies collaboratively; b) STOPAIDS led the consortium in an online workshop to develop a joint advocacy strategy, and to develop shared talking points for external speaking by all consortium members; c) Over the course of the two-year study, the consortium held regular informal discussions of emerging news relating to digital health and human rights, and held monthly strategic calls with guest lecturers on topics related to the study topic, discussing emerging observations collectively in reference to these presentations; d) Researchers traveled between countries to participate and support each other during the data-gathering and to discuss initial observations; and e) Consortium members co-organized webinars and conference panels at which we presented our analyses to colleagues and the public, and we discussed these as a consortium before and afterwards.

In this way, while data-gathering was underway, the consortium gradually developed a shared analysis of the benefits and risks of the digital transformation in health. This provided a foundation for our collective interpretation, described below.

7. How have research partners collaborated in interpreting study data?

The research team in each country held debrief sessions after each FGD and KII and discussed collective observations as the study was underway, capturing these in written reports to accompany the transcripts. SLDM, TS, KL and AM presented the draft codebook to the consortium for revision and input. They also conducted initial qualitative analysis of data and presented draft findings to the consortium on the monthly strategic calls for input. The local researchers presented the draft findings and policy recommendations to study participants in national virtual workshops for discussion and input.

SLMD presented a final analysis to the full consortium at an in-person workshop convened by KELIN in Nairobi. The local researchers then presented feedback from the validation workshops. The findings were reviewed, discussed and revised by the consortium. Local researchers led the presentation of findings and policy recommendations to the project advisory committee.

8. How were research partners supported to develop writing skills?

Local researchers (NM, NW, TI, IK and TP) collaborated to draft two inception papers based on the initial desk review of laws and policies, with mentoring and feedback from senior

managers and SLMD. SLMD and other senior managers in the consortium have also identified opportunities for young researchers to write about the study and have mentored them to write a book chapter, blogs and a chapter of an NGO report based on the study findings.

As most of the research partners have not experienced writing for a peer-reviewed publication before, the process of co-authoring a previous commentary for BMJ Global Health, as well as co-authoring this article, have also provided opportunities for some research partners from civil society to learn about the peer-review process.

9. How will research products be shared to address local needs?

The research has been used by GNP+, KELIN and STOPAIDS staff to collaboratively develop a policy brief in user-friendly language, and to translate it into Spanish. The policy brief and research was presented in two online webinars with experts from the research consortium and from UNDP and WHO, with consortium partners recruiting hundreds of participants from the study countries to participate. STOPAIDS, GNP+ and KELIN also convened online discussions through the RightsCon conference to share the research findings, as well as in online youth workshops and in briefings for young people living with HIV. National organizations in the consortium have also presented the research findings within their own countries, and have been invited to speak to international organizations, UN agencies and national governments about the research findings.

In addition, GNP+, KELIN and STOPAIDS are also collaborating to support the mandate of the UN Special Rapporteur on the Right to Health, Dr. Tlaleng Mofokeng, to hold consultations, develop submissions, and publish her report to the UN Human Rights Council on digital technologies, innovation and the right to health. They will then use the report to hold national and regional dissemination meetings with other civil society partners.

10. How is the leadership, contribution and ownership of this work by LMIC researchers recognised within the authorship?

The researchers who participated in the study are all listed as co-authors. We acknowledge, however, that the first author is based in a high-income country. The primary reason for this is that she led the project and drafted the article.

11. How have early career researchers across the partnership been included within the authorship team?

The majority of co-authors are early career researchers (TP, TO, IK, NM, AM, KL).

12. How has gender balance been addressed within the authorship?

Three authors are male (AM, TS, TW, CN) and eight authors are female (SD, TP, IK, TI, NM, EA, NW and KL). We feel that given the under-representation of women in digital design and governance, it is an important contribution that we have a majority of women from LMICs listed as co-authors.

13. How has the project contributed to training of LMIC researchers?

The authorship team is primarily composed of early career researchers from LMICs. For most of the co-authors, this is the first peer-reviewed publication, and their first experience participating in a social science study, and thus the project has significantly enhanced their skills and experience in research and analysis.

14. How has the project contributed to improvements in local infrastructure?

This project has not directly contributed to improvements in local infrastructure.

15. What safeguarding procedures were used to protect local study participants and researchers?

We have consulted closely with local researchers and civil society groups to identify and address any security risks proactively.